

# The ‘Fears’ of Disclosing HIV Status to Sexual Partners: A Mixed Methods Study in a Counseling Setting in Ghana

D. Obiri-Yeboah · D. Amoako-Sakyi ·  
I. Baidoo · A. Adu-Oppong · T. Rheinländer

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**Abstract** Encouraging disclosure within a trusting and supportive environment is imperative in dealing with HIV/AIDS related stigma. However, disclosure rates and the factors that influence it are vaguely understood in African societies. This study aimed at determining the disclosure rate and factors that influence disclosure in Cape Coast, Ghana. In-depth interviews of 15 peer educators and a survey of 510 PLHIV were used in a mixed methods study design. Majority of the study participants (78.6 %) had disclosed their HIV positive status to their sexual partners. Although peer educators in this study portrayed the overall outcome of disclosure to be negative, 84.0 % of disclosers were accepted by their partners without negative consequences after disclosure. This study suggests that the

existing support services ill prepares newly diagnosed HIV positive clients and hampers disclosure initiatives. Providing comprehensive support services and re-training peer educators may be crucial in creating a safe disclosure environment in Ghana.

**Keywords** HIV · Disclosure · Sexual partners · Ghana

## Introduction

While the overall global incidence of HIV seem to have stabilized in recent years, the incidence of HIV among married or cohabiting heterosexual couples has remained high in many parts of Africa [1–3]. The estimated adult national HIV prevalence in Ghana was 1.37 % in 2012 with an estimated 235,982 persons living with HIV and AIDS. Among adults, 7,139 new infections are estimated to have occurred in Ghana in 2012 [4]. A central factor influencing the incidence of HIV among married and cohabiting couples mentioned in studies in the African setting is HIV disclosure status, defined as the readiness of people living with HIV (PLHIV) to inform their sexual partners of their HIV positive status.

A study in Ghana showed that the issue of disclosure within a trusting and supportive environment may be an important strategy in dealing with AIDS related stigma [5]. In another study in Ghana, the sexual risk behavior of adults living with HIV was found to be affected by whether they had disclosed to their sexual partners or not [6]. Increasingly, disclosure of HIV status to sexual partners by PLHIV is being recognized as a crucial part of HIV prevention. The benefits of disclosure are several. First, the infected partner will be able to adhere to schedules given for clinical care and antiretroviral therapy (ART) with

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This article is about the issues of disclosure of positive HIV status to sexual partners. This is discussed in the context of the Ghanaian socio-cultural setting and the issues of navigating intimate relationships by people living with HIV. The discussion helps reveal possible strategies to help made disclosure of HIV positive status to sexual partners more likely to occur in a safe manner and thus lead to the potential benefits stated in literature.

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D. Obiri-Yeboah (✉) · D. Amoako-Sakyi  
Department of Microbiology, School of Medical Sciences,  
University of Cape Coast, PMB, Cape Coast, Ghana  
e-mail: d.obiri-yeboah@uccsms.edu.gh

I. Baidoo  
ART Center, Cape Coast Teaching Hospital,  
P.O. Box CT 1363, Cape Coast, Ghana

A. Adu-Oppong  
Department of Community Medicine, School of Medical  
Sciences, University of Cape Coast, Cape Coast, Ghana

T. Rheinländer  
Department of Public Health, University of Copenhagen,  
Copenhagen, Denmark

support from the partner as shown in studies in Uganda, Zambia and China [7–9]. Also, the infected partner can better deal with the initial confusion and despair with the emotional and practical support received from the partner as demonstrated in studies from San Francisco, and Uganda [10, 11]. In situations where discordant couples decide to have a child, they can be supported to achieve a pregnancy with reduced risk to the uninfected partner if disclosure of the positive status has occurred [12]. In addition, if found to be infected, the partner can know his or her HIV status in the early asymptomatic phase, which is a strong correlate for slow disease progression and better prognosis compared with people diagnosed in the symptomatic phase. This has been shown in studies across diverse settings such as Nigeria, South Korea and Georgia [13–15]. Finally, prevention of mother to child transmission (PMTCT) of HIV also has a better chance of succeeding when partners disclose their HIV status. Many studies in developing African countries including Ghana have indicated that when men are aware of the status of their HIV positive pregnant women, they are often supportive and encourage adherence to ART and other PMTCT interventions [16–19]. However disclosing HIV status to an intimate partner, presents with many moral, emotional and relational challenges. Fear of domestic violence, economic and emotional repercussions from partners etc. have been documented in studies in various settings including South Africa and Nigeria [20–22].

The policy on disclosure in Ghana requires that all newly diagnosed clients receive counseling on disclosure and partner notification. The clients are encouraged and allowed to disclose either by themselves at home or in the presence of the counselor to their sexual partners. The policy does not allow counselors to disclose a client's HIV status to partner(s) without consent from the positive client. Hence, counselors need to be better informed on the factors that influence client's willingness to disclose their HIV status. However, literature on the rate of disclosure to sexual partners, disclosure outcomes and factors influencing disclosure in the Ghanaian socio-cultural context are scarce. An important first-step in encouraging disclosure is to establish the disclosure rate in a Ghanaian setting and adequately understand what informs the decision to disclose or not and the implications this can have on disclosure support initiatives in Ghana. This study therefore aimed at determining the disclosure rate and factors that influence disclosure in Cape Coast, Ghana. This is done in order to suggest ways to help HIV positive clients to disclose their HIV status in safe ways to ultimately improve their social, reproductive and health prospects. Findings from this study may provide fresh insights on how HIV positive clients can be counseled to increase disclosure rates in Ghana. Increased disclosure

rates may in turn improve their prognosis, social and reproductive health.

## Methods

This study was a mixed method study among HIV positive clients receiving care in the Cape Coast Teaching Hospital (CCTH) in the Cape Coast Metropolis of Ghana. This facility has a well-established HIV clinic with about 3,000 registered clients. In 2011 the Central region recorded the highest HIV prevalence of 4.7 % and the Cape Coast metropolis had the highest HIV prevalence across the country of 9.6 %. This was a significant rise from the 2010 regional prevalence of 1.7 and 2.2 % for Cape Coast Metropolis and these influenced the choice of this as an important study site.

The proposal for this study was first reviewed by the ethical review committee of the School of Medical Sciences of the University of Cape Coast, Ghana. Final ethical approval was obtained from the institutional review board of the University of Cape Coast, Ghana. Semi-structured in-depth interviews were conducted with 15 purposively selected key-informants (Ten females, five males, aged between 28 and 48 years). Initially five peer educators at the ART center who are themselves leaders in various associations supporting PLHIV in the region were recruited and interviewed. Through snowball sampling [23] ten additional leaders were identified and recruited from the various associations of PLHIV across the region. These participants, by their positions had in-depth knowledge of the situation of a larger number of PLHIV and hence could offer an insider perspective on the challenges of disclosure to sexual partners. The interviews were of a narrative nature [24, 25] with clients allowed to respond to four open ended questions and sharing their stories and experiences:

1. From your own experience and that of members of your association, what can you tell me about the issue of disclosure of HIV positive status to sexual partners?
2. Tell me some of the stories you hear about the experiences of people when they disclose their HIV status
3. Do you think it is good to tell your sexual partner about your HIV status?
4. What do you think could be done to make it possible for people to disclose to their sexual partners?

Each interview lasted between 45 and 60 min and was conducted in the mother tongue of Fante, or English as preferred by the informants. Written informed consent was obtained from all respondents before the interviews were conducted. The responses were transcribed ad verbatim into English and analyzed using a thematic approach [24, 26] in which text was thoroughly read through several times, coded and organized into main themes. The themes which are

presented in this paper include the perceptions of real or imagined ‘fears’ associated with disclosure strategies, experiences with managing intimate relationships when disclosing and health care implications of disclosure and non-disclosure.

All the interviews were conducted by the first author, a female doctor who has an extensive knowledge in supporting PLHIV and has been actively engaged in diagnosis and treatment of HIV clients in the region and the specific clinic since 2006. The author knew all 15 key-informants prior to the interviews and could therefore relate to their experiences and build rapport for the interviewees to express themselves freely. Based on the findings from interviews, a structured questionnaire in English was developed and used to gather information from a total of 510 respondents on factors influencing disclosure. The maximum sample size required at 95 % confidence interval and 50 % response distribution and a population size of 20,000 was 377. Adjusting for non-response or incomplete responses a total of 510 clients were surveyed. Respondents were systematically recruited among PLHIV visiting the clinic for their routine management on each clinic day between November 2012 and March 2013. Inclusion criteria were: being HIV positive, being 18 years or above and being sexually active. After obtaining written informed consent, respondents who spoke English answered the questionnaire themselves. Those who could not read English were assisted by three research assistants, who had all received training by the first author in confidentially, explaining and obtaining written informed consent, administering the questionnaire in the local language of Fante and managing the data collected. The themes of the questionnaire included: socio-demographic characteristics, how and why they disclosed or not disclose their HIV status to sexual partner(s), the effect disclosure or lack of it on their lives and their intimate relationships, and their views on the current disclosure policy in Ghana and suggestions to help PLHIV disclosure.

Questionnaire data was entered into STATA statistical software without patient identifiers and analyzed (Release10; Stata Corporation, College Station, TX, USA). Descriptive analyses were conducted to generate frequencies and percentages. Person Chi square test was done for some categorical data to determine statistical significance among groups. A  $p$  value of  $\leq 0.05$  was deemed significant. Univariate and multivariate analysis were conducted to test for associations between demographic characteristics and disclosure.

## Results

### Demographic Characteristic of Study Participants and Disclosure Status

Table 1 shows the demographic characteristics of the participants, the circumstance of HIV diagnosis and partners’

HIV status. The mean age of the 510 total participants from the quantitative data was 41.26 years with majority being women (82.5 %), and the majority belonging to the Christian faith (92.1 %). Most participants were either living together with a partner in a legal marriage (49.8 %) or cohabiting with a sexual partner without being legally married (30.2 %). The rest lived alone and reported having occasional sexual partners.

Most respondents reported being diagnosed with HIV as part of a health provider initiated testing at a health facility due to symptoms suggestive of HIV/AIDS ( $n = 383$ , 75.1 %). This was followed by women who were tested at antenatal clinics as part of routine HIV testing for pregnant women ( $n = 65$ , 12.7 %).

Whiles 78.6 % ( $n = 401$ ) of respondents had disclosed their HIV positive status to their sexual partners, only 48.2 % ( $n = 246$ ) of them knew of the HIV status of their sexual partners. Twenty-three percent of respondents did not know if their partners had tested for HIV and 22.4 % reported that their partners had out rightly refused to be tested.

### Factors Associated with Disclosure and Disclosure Process

Out of 510 respondents, 78.6 % ( $n = 401$ ) had disclosed their HIV status to partners at the time of the survey, while 21.4 % ( $n = 109$ ) had still not disclosed. Table 2 shows the associations between demographic and socio-economic factors with the odds of disclosing HIV status to partners. The results shows that those who conceal their HIV status from partners are significantly younger (median age = 38.11 years.) than those who disclose (median age = 42.11 years) ( $p < 0.0001$ ). Those living alone with occasional sexual partners were less likely to disclose their HIV status compared to those who are married ( $p < 0.05$ ; OR = 0.52; CI (0.30–0.92)). Interestingly, cohabiting individuals were more likely to disclose their HIV status to partners compared to married ( $p < 0.0001$ ; OR 2.39 (1.34–4.35)).

The results also revealed some important challenges relating to disclosure and relationships: those who had not disclosed their own HIV status to their partners had a higher likelihood of having partners who refused to test ( $p < 0.0001$  OR = 0.01 CI (0.00–0.05)). In addition, the odds of having their partners disclose their HIV status was greatly reduced for those who had not disclosed themselves ( $p < 0.0001$  OR = 0.01 CI (0.00–0.05)). These findings point towards some crucial barriers for disclosure related to relationship dynamics, which will be further investigated in the qualitative data.

Next stage of the analysis concentrated on investigating the process of disclosure including the motivating factors leading to a decision to disclose and the responses of sexual partners (See Table 3). In total, 84.0 % ( $n = 337$ ) of

**Table 1** General characteristics of study population

Characteristics	<i>N</i> = 510 (%) [range]
Mean age (years)	40 (20–75)
<i>Sex</i>	
Male	89 (17.5)
Female	421 (82.5)
<i>Disclosure status</i>	
Disclosed	401 (78.6)
Undisclosed	109 (21.4)
<i>Level of education</i>	
No education	143 (28.0)
Primary school	79 (15.5)
Junior secondary school	228 (44.7)
Secondary and above	60 (11.8)
<i>Religion</i>	
Christian	470 (92.1)
Moslem	32 (6.3)
Traditional	8 (1.6)
<i>Relationship type</i>	
Single (with occasional sexual partners)	16 (3.1)
Married	254 (49.8)
Cohabiting (lives with a partner but not legally married)	154 (30.2)
Divorced (with occasional sexual partners)	47 (9.2)
Widowed (with occasional sexual partners)	39 (7.6)
<i>Employment status</i>	
Employed	424 (83.1)
Unemployed	86 (16.9)
<i>HIV diagnosis</i>	
Health provider initiated test	383 (75.1)
Client initiated walk-in test in a health facility	44 (8.6)
During a community testing and counseling campaign	18 (3.5)
Routine testing and counseling at antenatal clinic	65 (12.7)
<i>Partner's HIV status</i>	
Positive	115 (22.5)
Negative	131 (25.7)
I do not know if my partner tested	119 (23.3)
Partner tested but has not disclosed to me	31 (6.1)
Partner refuses to be tested	114 (22.4)

disclosers experienced a positive outcome as their partners accepted their HIV test results without any negative reactions while 16.0 % ( $n = 64$ ) of disclosers reported a negative reaction. As many as 82 % ( $n = 329$ ) disclosed within the first week after diagnosis. When asked what influenced them to disclose, the majority said it was personal meaning they disclosed on their own initiative because they felt it was important to share the results with their sexual partners ( $n = 210$ , 52.4 %). This was followed by those who decided to disclose mainly due to the counseling they received on disclosure and partner notification by the health personnel ( $n = 172$ , 42.9 %).

The preferred place for disclosure was at home alone with the partner ( $n = 206$ , 51.4 %) followed by disclosing in the presence of a counselor in the health facility ( $n = 181$ , 45.1 %). Most participants, 84.4 % ( $n = 339$ ) did not regret their decision to disclose irrespective of the outcome and 85.5 % ( $n = 343$ ) found their partners to be supportive of their clinical care.

A separate analysis was conducted for those 109 respondents who had not disclosed their HIV status yet, to identify reasons for and the effects of not disclosing (see Table 4). The main reason given for not disclosing was the fear that disclosure would lead to the partner ending the

**Table 2** Factors associated with disclosure or non-disclosure

Factor	Disclosure status		P value	OR (95 % CI)
	Disclosed [N (%)]	Not disclosed (%)		
Age: median	42.11	38.11	<0.0001	
<i>Sex</i>				
Male ( <i>ref</i> )	76 (19)	13 (11.9)	–	
Female	325 (81)	96 (88.1)	0.815	1.09 (0.54–2.20)
<i>Marital status</i>				
Married ( <i>ref</i> )	225 (56.1)	29 (26.6)		
Co-habiting	97 (24.2)	57 (52.3)	0.004	2.39 (1.31–4.35)
Lives alone with occasional sexual partners	79 (19.7)	23 (21.1)	0.024	0.52 (0.30–0.92)
<i>Educational level</i>				
No education ( <i>ref</i> )	112 (27.9)	31 (28.4)	–	
Primary	62 (15.5)	17 (15.6)	0.611	1.20 (0.59–2.43)
J.S.S	182 (45.4)	46 (42.2)	0.511	1.20 (0.61–2.09)
Secondary and above	45 (11.2)	15 (13.8)	0.581	0.80 (0.37–1.74)
<i>Employment status</i>				
Employed ( <i>ref</i> )	338 (84.3)	86 (78.9)	0.253	0.72 (0.40–1.27)
Unemployed	63 (15.7)	23 (21.1)		
<i>Religion</i>				
Christian ( <i>ref</i> )	371 (92.5)	99 (91.0)	–	
Moslem	24 (6.0)	8 (7.3)	0.787	1.25 (0.25–6.28)
Traditional	6 (1.5)	2 (1.8)	1.000	1.00 (0.17–5.96)
<i>HIV diagnosis</i>				
Health provider initiated ( <i>ref</i> )	297 (74.1)	86 (78.9)	0.360	
Client initiated walk-in testing in a health facility	38 (9.5)	6 (5.5)	0.232	0.38 (0.08–1.85)
Community testing and counseling Campaign	16 (4.0)	2 (1.8)	0.788	0.79 (0.14–4.35)
Routine HIV testing and counseling at ANC	50 (12.5)	15 (13.8)	0.269	0.43 (0.10–1.91)
<i>Partner's HIV status</i>				
Positive ( <i>ref</i> )	113 (28.7)	2 (1.8)	–	
Negative	125 (31.2)	6 (5.5)	0.972	0.97 (0.13–6.97)
Do not know if partner has tested	117 (29.2)	2 (1.8)	0.212	0.36 (0.07–1.80)
Partner has tested but has not disclosed to me	11 (2.7)	20 (18.3)	<0.0001	0.01 (0.00–0.05)
Partner refuses to be tested	35 (8.7)	79 (72.5)	<0.0001	0.01 (0.00–0.05)

ANC antenatal clinic

relationship ( $n = 39$ , 35.8 %). Also, 21.1 % feared that their partners would make their HIV positive status public while 13.8 % said they had not disclosed because they were not counseled to do so by the health personnel. For 11.9 % it was the fear of abuse, be it physical or verbal by their partners that had kept them from disclosing. A total of 43.1 % ( $n = 47$ ) reported that non-disclosure led to serious problems with negotiating condom use resulting in unprotected sex with partners on occasions. Regardless of these consequences of non-disclosure, it is worrying to see that 48.8 % ( $n = 53$ ) of non-disclosed respondents still felt that they were still not ready to disclose their HIV status to their partners.

#### The 'Fears' Associated with Disclosure; Real or Imagined?

Analysis of qualitative data offered further insights and provided context for the quantitative data represented in Table 3. The key informant interviews revealed lots of sentiments and fears about negative reactions and effects on relationships associated with disclosure. A collective narrative of emotional distress seemed to be shared and generally accepted among peer educators who verbalized many negative stories with dreadful outcomes for the disclosers during interviews: “*I know many at the beginning who were sacked, many could not get proper food to eat*

**Table 3** Disclosure process and outcome

Variables (total respondents = 401)	N (%)
<i>How long did it take you to disclose?</i>	
<1 week	329 (82.0)
1–3 weeks	32 (8.0)
1–6 months	26 (6.5)
7–12 months	8 (2.0)
>1 year	6 (1.5)
<i>Who or what influenced your decision to disclose?</i>	
I did it on my own initiative	210 (52.4)
The counselor	172 (42.9)
Advice from another positive client	5 (1.2)
My partner insisted on knowing my results	14 (3.5)
<i>Where and how was disclosure done</i>	
At home alone with my partner	206 (51.4)
At the hospital in presence of counselor	181 (45.1)
My partner accidentally found out	1 (0.2)
By phone	7 (1.7)
Asked a trusted friend/relative to disclose	6 (1.5)
<i>Response of partner after disclosure</i>	
Accepted it without a problem	337 (84.0)
Became verbally abusive	28 (7.0)
Became physically abusive	7 (1.7)
It led to divorce/separation	28 (7.0)
Disclosed to other people	1 (0.2)
<i>Partners attitude towards your clinical care</i>	
Supportive	343 (85.5)
Not supportive	58 (14.5)
<i>In hindsight, would you disclose your HIV status?</i>	
Yes	339 (84.4)
No	46 (11.6)
Not sure	16 (4)

and many died. It was sad. I can think of many people at the time that died and I think not from HIV but hunger - all because they told (about their HIV status)...” (Female, 48 years, not disclosed).

It is worth noting that of the 15 peer educators interviewed, 10 had disclosed and of these 4 personally experienced negative reactions mainly in the form of emotional and verbal abuse. One person had the relationship ending as a direct result of disclosing. None of the interviewees were physically abused and yet, all 15 of them narrated many stories of negative consequences of disclosure to sexual partners. It thus appeared as if among the leaders and peer educators interviewed, there was a persistent construction of the idea that disclosure was very likely to lead to a negative consequence. One male peer educator who had disclosed his HIV status said: “Every day they are

talking (at the association meetings) about what happened to them when they told their husbands or boyfriends” (Male, 35 years, Disclosed). A woman who had not disclosed added: “Some of the women (at the meeting) say they were insulted and some were even beaten....” (Female 43, not disclosed).

Among the key informants, there also seem to be a perception that gender was influencing decisions to disclose or not. Thus, male and female informants, disclosers and non-disclosers alike, said that disclosure was more complex for women. A woman who had disclosed said: “This is very difficult especially for us women. We are always worried about what the men will do to us” (Female, 45 years, Disclosed). Men seemed to agree with the idea that women have more to fear when disclosing. A married man who had disclosed and still lived with his wife said: “In fact the women are suffering more than the men. When the men go home (and disclose to their partners) their women don’t fight them too much” (Male, 46 years, Disclosed).

#### Strategies and Procedures for Disclosing

With these fears in mind, many seemed to think that the place and procedure of disclosure was key to the outcome of disclosure. Both disclosures and non-disclosures offered personal suggestions on locations and strategies to disclose in ways that would address some of these feared outcomes. Suggestions mainly referred to using health facilities as settings and peer counselors as semi-professional intermediaries in the disclosure process. One male who had been through disclosure process explained: “I think it is better when the nurse is there and we tell at the hospital than those who do it alone in the house” (Male, 44 years, Married, Disclosed in health facility, Partner HIV negative, still living together). A peer educator further stated: “I think you should use those of us who are leaders in our associations (HIV support networks) to find those who have not told their partners and let’s help them and see how it can be done without causing so much trouble” (Male, 48 years, Married, Disclosed at home alone to partner. Partner also HIV positive, still together).

Concrete strategies as to how to convey the feared message were also needed: “I think some people get into trouble when they tell because of how they say it. Some go and say (to their partner) that you have given me AIDS so come with me (to the hospital), and then the partner gets very angry especially the men. So I think if we bring them (to the health facility), you (the health staff) should do the telling. If we want to tell them at home then teach us better how to tell them” (Female, 64 years, Widowed, Disclosed at home to partner and lead to separation).

**Table 4** Reasons and effects of non-disclosure

	N, (%)
Total respondents = 109	
<i>Reasons for non-disclosure</i>	
I was not counseled to do so	15 (13.8)
Fear of abuse (physical or verbal)	13 (11.9)
Fear of the relationship ending	39 (35.8)
Fear of him/her making it public	23 (21.1)
I plan to disclose at a later date	19 (17.4)
<i>Effect of non-disclosure</i>	
I cannot insist on using condoms	47 (43.1)
I have to hide to attend clinic	31 (28.4)
I have to hide my medication	22 (20.2)
My partner wants a child and I can't explain my reluctance to have a child	7 (6.4)
I have no problems	2 (1.8)
<i>Current position on non-disclosure</i>	
I am ready to disclose	24 (22.0)
I am still not ready to disclose	53 (48.6)
My partner has not earned the right to know	16 (14.7)
I do not currently have a sexual partner	16 (14.7)

#### Disclosing or not Disclosing; a Question of Managing Intimate Relationships

The quantitative data identified several serious problems in terms of knowing partner's HIV status. Among those who had disclosed 40.6 % ( $n = 163$ ) did not have any idea of their partners status either because the partner refused to test, had tested but did not disclose or they did not know if the partner had tested. Among those who had not disclosed, an overwhelming majority, 92.6 % ( $n = 101$ ) had no idea of their partners HIV status. Many interview participants made several references to the fact that both partners knowing their status is key to navigating intimate relations after HIV diagnosis. A participant who disclosed and still live with an HIV positive partner said: "If you are the one being positive, then you know how to protect the negative one so she/he does not get it" (Male 46, Married, Disclosed, Partner also HIV positive). Informants who had disclosed and were still living with their partners added that disclosure was also necessary to maintain trust and sexual activity in the relationship.

Another challenge identified in the survey in dealing with an intimate relationship with or without disclosure was the issue of condom use (Table 4). The qualitative data collaborated the finding that negotiating condom use was a major challenge particularly for non-disclosing females. A married woman who had not disclosed and lived with her husband explained the challenge: "All the time they (health personnel) talk to us (people living with HIV) about condoms and sometimes you people (health staff) even give some to us free (condoms) but it is very hard to use it if the man does not agree. You, the woman, cannot force it...."

(Female 43, Not disclosed, Married). Negotiating condom use and the issue of having children while HIV positive were indicated as two distinct problems in the questionnaire, but the qualitative data showed that these issues are often interlinked. A peer educator expressed a similar concern: "This is why (they cannot say no to having unprotected sex) many of our women (HIV positive) are also getting pregnant because they don't know how to make their men use condom all the time...." (Male 46, Married, Disclosed, Partner also HIV positive). A married male participant explained how this challenge gets more complex due to the strong social norms in Ghana which expect women to agree with their husband's demand for children: "And if the woman uses any family planning the man will get very angry if he wants more children. Here (in Ghana) the woman cannot just decide not to give birth. So for a woman who does not say (why she doesn't want to have sex), it will be a big fight all the time in the house" (Male, 48 years, Married, Disclosed. Partner is also HIV positive).

#### Impact on Health and Health Seeking Behavior

Many participants interviewed, particularly women, felt that disclosure and non-disclosure had links with issues of mental and emotional health as well as health seeking behavior of the HIV positive person. A married participant who had not disclosed explained it this way: "I think when you are told you have HIV; it is so heavy for you to carry alone. I think if you don't tell anyone you will always feel sad and guilty" (Female 43, Disclosed, Married). To another peer educator, there was also a link to religious

believes: “*It is good to make peace with Allah and I believe telling (about the diagnosis) will help to make that peace. Allah will not forgive you if you do not*” (Female 40, Married, Disclosed, Partner HIV negative). A woman who has lived with the diagnosis of HIV since 2006 shared this experience: “*With this disease, you need someone to talk to. If not, you will be so sad. Sometimes you even think death is better, but if you have someone, you may feel a little better.*” (Female, 64 years, Widowed, Disclosed).

The effects of non-disclosure on health seeking behavior was highlighted in the quantitative data with 28.4 % ( $n = 31$ ) and 20.2 % ( $n = 22$ ) of non-disclosers having to hide medicines and clinic visits respectively (Table 4). The narratives of the informants furthermore showed how serious non-disclosure was for adherence to HIV treatment. A male non-disclosed informant explained: “*I hide my medicine because she (the wife) can read, so if she sees it I am sure she will know what it is. So when she is there and it is time for me to take the drug then I am in trouble. So sometimes I have to get her money and send her to buy maybe a drink or something she will like, then I take it when she goes. All this waste of money, hmm.*” (Male, 28 years, not disclosed, cohabiting). A woman added: “*Many of us (HIV positive) are hiding to come to the clinic*” (Female, 48 years, not disclosed). In contrast, those informants who did not conceal their HIV status and treatment, experienced that they could get support, practical as well as emotional, when attending to treatment. One man who had disclosed to his partner said: “*Look at me, I come here freely, I don’t hide. At the beginning she was bringing me because I was sick and could not travel alone. I don’t hide my medicine and even if I am forgetting because I am doing something, she will bring it*” (Male, 44 years, Married, Disclosed, partner HIV negative).

## Discussions

### Strengths and Limitations

The main strength of this study is the mixed methods approach which included both survey data and in-depth qualitative interview data [27–29]. The qualitative approach provided rich context and meaning behind the quantities obtained in the survey and was also instrumental in the first phase of the study to design a culturally adjusted and comprehensive disclosure questionnaire informed by ‘expert-patients’ who had a deep insight into the disclosure dilemmas of many PLHIV in the region. This study relied on self-reported disclosure status and therefore liable to social desirability bias, a type of response bias. This limitation was mitigated by phrasing questions to be as neutral as possible. In instances where respondents were

not literate and had to be assisted in completing the questionnaire, trained research assistants posed questions in a neutral manner with a neutral demeanor. In addition, respondents were desensitized to social desirability bias prior to obtaining informed consent by assuring them that there was no right or wrong answers.

Also the lack of insight into the perspective of counsellors and other related health professionals involved in the disclosure process is a limitation. Their narratives would have added more insight into the disclosure process and helped identify specific potential health facility interventions to address the issues from both the part of health professionals and the clients. This study did not include narratives of sexual partners of HIV positive clients who disclosed. Hence we may not have identified all factors influencing disclosure outcomes. The study design is also liable to recall bias. For the quantitative study, sampling was not stratified by gender, hence analysis may not statistically represent gender differences.

### Disclosure Rates and Disclosure Counseling

Disclosure and sexual partner notification is promoted as an important HIV prevention strategy globally. Despite the challenges associated with disclosure, many studies in Africa including Cameroun, Nigeria, Malawi and Zimbabwe have reported high disclosure rates around 80 % [22, 30–32]. This study also found a similar disclosure rate of 78.6 %. The high disclosure rate notwithstanding, disclosing is not without complicated emotional and relational consequences.

The data reveals that the preferred place for disclosure was alone with the partners at home or at the clinics in the presence of the counselor. The qualitative data further shows that there is a need for counselors to support clients on how to disclose as this can reduce some of the negative reactions of partners and families. Similar studies on disclosure have also concluded that disclosing is complex and needs supportive counseling [33] including counseling on when it is best and safe to disclose [11]. These findings have implication for counselors as well as clients: while existing counseling guidelines do include recommendations to clients and counselors on when and where to disclose, this could be further improved by including more active ‘disclosure role playing’ in the counseling room. This could enable clients to practice how to handle possible reactions of partners supported by counselors [34].

### Imagined Fears and Reconstructing Narratives of Distress

This study revealed some important contrasts between the high positive disclosure outcomes and a strong negative



constructed narrative of disclosure presented by peer educators. The danger of this discrepancy is that, if peer educators are the main source of information on disclosure to newly diagnosed members, the ‘fears’ might overshadow the many positive effects of disclosure and lead to postponement or refusal to disclose.

Medley et al. in their review of articles on disclosure among women in developing countries found that many of these articles reported that a higher proportion of study participants had positive outcomes following disclosure of HIV positive status [17]. Seid et al. in a much recent study conducted in Ethiopia also reported that while many non-disclosers said they had not disclosed to their sexual partners due to fear of abuse, relationship ending etc. 74.5 % of those who disclosed actually were accepted by their sexual partners [35]. This raises the suspicion that narratives of adverse outcomes of disclosing are exaggerated and perceived rather than real. It is imperative that counsellors help peer educators to reconstruct their narratives of distress to make it more balance, objective and evidence-based. Peer educators also need to be informed about the effect of their narratives of distress including the unintended negative effects of preventing clients from disclosing. It may be helpful to retrain peer educators to truly and effectively advocate for disclosure to sexual partners, thus supporting the national prevention strategy.

#### Security in Relationships

This study found that those living alone with occasional sexual partners were less likely to disclose their HIV status compared to those who are married. Many studies have commented on the role of the type of relationship on disclosure. In their study on disclosure Patel et al. reported that women who disclosed to current husband/partner were more often currently married than women who did not disclose (78 % vs. 17 %;  $p < 0.0001$ ) [32]. But the qualitative data from this study shows that this issue is more complex and might also be related to gender norms in relationships. Similar findings are reported from other places showing that the decision to disclose or not might be more related to how secure particularly women feel in the relationship than being legally married or not [20, 36]. Moses and Tomlinson in their qualitative study on disclosure among pregnant women also comment on the complexity of the issue. They found that the narrative on disclosure was a fluid one among these women and is affected by many considerations than marital status [37]. This implies that all newly diagnosed HIV clients must be supported equally in dealing with this issue without assuming that being married or not offered an easy way. The implication of the high proportion of sera discordance among partners found in this study is that disclosure is key to partner testing in the

Ghanaian setting and must be supported at the national level as a key strategy to help reduce the HIV transmission rate among couples whether married or not.

#### Reproductive Health and Disclosure

Another area where disclosure presented a challenge was in the area of sexual and reproductive health decisions. This study revealed that these issues are more challenging for women than men, in cultural settings in Africa including Ghana where women traditionally are not expected to be actively involved in decisions such as condom usage and having children [38–40]. Pettifor et al. in their study in South Africa reported on the effect of this power dynamics on the use of condoms by HIV positive women and the link to HIV transmission. Other studies have thus made the point that addressing issues of women’s reproductive rights in a country will also contribute to dealing with the challenge of women being active in their reproductive health decisions [21]. This implies that disclosure counseling must expand services to female clients to also include contraceptive negotiation skills and education of sexual partners [30]. Couple therapy and the involvement of male partners in particular in the counseling process has been highlighted as a specific strategy in reducing particularly mother to child transmission of HIV (MTCT) [1, 16, 41]. This could potentially be a fruitful strategy in Ghana to empower women to discuss their reproductive rights including the negotiation of contraceptives with their partners.

#### Conclusions

This study applied a mixed method approach to investigate disclosure rates, the disclosure process, and the experiences of managing intimate relationships during disclosure counselling in an urban regional hospital setting in Ghana. The study found high rates of disclosure and identified home-based or counsellor assisted disclosure as the preferred strategies for safe disclosure. But the study also identified important underlying challenges for disclosure including a strong negative narrative of the ‘fears of disclosure’ held by peer educators, the insecurities in relationships, gender norms, and a need for more support for disclosure process. The study recommends that to strengthen disclosure initiatives counsellors need to be equipped with the necessary skills with emphasis on supporting newly diagnosed HIV positive clients, with special focus on counselling women on the disclosure process and dealing with partners possible reactions. Couples must be counseled effectively on how to navigate insecurities in relationships while living with HIV. In addition, it is highly recommended that peer educators among PLHIV be helped to change their negative narrative about

disclosure outcomes so they can have a positive impact on their peers and support a safe disclosure process. Clearly, counsellors have more to do in the Ghanaian setting to strengthen and support disclosure efforts hence the funders and administrative bodies governing the national HIV prevention strategy must also realize this and give the necessary attention to the work of counsellors and peer educators.

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