



Stigmatization, Status Disclosure and Support among HIV Positive Women in the Kumasi Metropolis of Ghana; a Qualitative Study

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Authors' contributions

Author DB designed the study. Authors DB and GDK contributed to data acquisition. Authors DB and DYQ analyzed and interpreted the data. Authors DB and DYQ wrote the first draft of the manuscript. Authors IA, AO and ONM critically reviewed the manuscript. All authors read and approved the final manuscript for publication.

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ABSTRACT

Background: HIV-related stigma and discrimination are impediments to mitigating the HIV epidemic, with women mostly affected. This qualitative study explored issues of stigmatization, disclosure of status and adherence to Antiretroviral therapy (ART) among HIV positive women.

Methods: This study was conducted in three ART centers in the Kumasi metropolis of Ghana. 23 HIV positive women aged 18-49 years and on Antiretroviral (ARVs) for treatment or prophylaxis for >3 months and 14 health workers at the ART centers were recruited. Three focus group discussions with 23 HIV positive women and 14 in-depth interviews with health workers were conducted.

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Participants were interviewed about their opinions and experiences on issues of stigmatization, status disclosure, social support and adherence to ART.

Results: Thematic analysis revealed that experience of stigmatization by HIV positive women leads to a default of ART. Some women who had disclosed their status had support from their partners whereas others experienced intimate partner violence and loss of financial support. Stigmatization and fear of divorce, rejection or abandonment were significant reasons for not disclosing HIV status.

Conclusion: HIV testing and counseling programs should provide guidance and strategies to best disclose status to help minimize abuse following disclosure.

Keywords: Status disclosure; social support; stigmatization; women; HIV.

1. INTRODUCTION

In 2016, approximately 36.7 million people were living with HIV worldwide, and 1.8million were newly infected [1]. Although the global HIV/AIDS epidemic is stabilizing, there exist an unacceptably high level of infection and uneven progress in many countries. Sub-Saharan Africa (SSA) for instance, being home to only 12% of the world's population, accounts for 71% of the global burden of HIV infection [1,2] and about 78% of people living with HIV (PLHIV) in SSA live in Eastern and Southern Africa [2,3]. According to the foundation for AIDS research [4], majority of the people living with HIV/AIDS are women. In Ghana, 270,000 people were living with HIV in 2016, with 160,000 (59%) of them being women aged 15years and above [5].

New HIV infections have declined substantially due to scale up and widespread coverage of antiretroviral therapy (ART). Across SSA, countries have shown a decline in new infections by more than 33% from an estimated 2.2million in 2005 to 1.8million in 2016 [3,6]. In Ghana, new infections reduced from 254,368 in 2008 to 250,232 in 2014 [7]. This success is related to ART adherence. Strict adherence is the most critical factor in ensuring ART success by providing sustained HIV suppression [8]. Without good adherence, treatment failure is likely, leading to avoidable HIV-related morbidity and mortality [9,10]. Some patients have reduced adherence from the onset and experience periodic lapses in adherence over the lifelong course of treatment. Even when the consequences of poor adherence to ART is appreciated, adherence rates remain sub-optimal, and this is attributed to factors such as stigmatization, which plays a central role in status disclosure and seeking support [11].

HIV related stigma and discrimination refers to prejudice, negative attitudes and abuse directed

at people living with HIV and AIDS [12,13]. It is seen as a product of social and cultural barriers that are in several forms and levels and affects multiple domains of an HIV individual's life, employment, and health care utilization [14–16]. Stigma and discrimination are impediments to mitigating the HIV epidemic [12,17–20]. According to UNAIDS report on World AIDS Day 2015, over 50% of people report having discriminatory attitudes towards PLHIV. In 35% of countries with available data [21] and findings from 50 countries, one in every eight persons living with HIV experiences some form of stigma and or discrimination and as a result misses out on accessing HIV related health services [19]. In SSA, much of the stigma and discrimination associated with HIV are directed to women.

Stigma and discrimination are considered as significant factors for individuals' disclosure of HIV status, engaging in HIV testing and seeking care and support [22–25]. In many settings, HIV positive women face more HIV related stigma than men especially in dominant male societies [26–31] such as Ghana. According to a UNICEF report, the fear of being discriminated if found favorable breaks down confidence to seek help and medical care [32] among HIV infected women. HIV positive women do not disclose their status for fear of intimate partner violence (IPV), rejection, and withdrawal of financial support [33–35]. The UNAIDS indicates that women who disclose their HIV status may be isolated because of HIV/AIDS-related stigma and discrimination [36]. This means that there is no certainty of social support once a woman is diagnosed with HIV.

On the other hand, disclosure, which involves telling someone about one's HIV positive status, contributes to reduced risk of HIV infection especially to a sexual partner and encourages the engagement in preventive behaviors such as condom use and HIV testing [37,38]. Disclosure of status enhances social support for PLHIV [22],

which helps to soften the impact of stigma and discrimination [20] and improves retention in care [39,40]. A study in Cameroun found that self-disclosure of HIV status to at least one person prior to treatment initiation was associated with the likelihood of retention [41]. Among pregnant women, spousal support for either antenatal care or HIV-related care services as a result of status disclosure has also been reported [42]. Social support in this study focuses on the functions of social support, which included emotional (esteem, concern), informational (suggestion, advice, information) and instrumental support (money, time, escort) [43,44].

In Ghana, rates of stigma and discrimination are relatively high [45]. Available estimates show that only 18% and 11% of Ghanaian females and males, respectively, have accepting attitudes towards PLHIV [46]. Stigma and discrimination had led to a refusal to access treatment, leading to death in some cases [47]. According to the Ghana Aids Commission (GAC) stigma against PLHIV remains the most significant challenge toward HIV-AIDS prevention and management [7]. Similar to other settings, a more extensive negative impact of HIV-related stigma on disclosure and response to HIV diagnosis has been found in women than in men [26]. HIV/AIDS was initially considered to be a women's disease in Ghana, and AIDS was explained as "Akosua Is Dying Slowly" [48] because of the higher prevalence of the disease among women (80% of PLHA) in the late 1980s. More recent data show that this uneven diagnosis rates among men and women still persist [5]. A qualitative documentation of HIV women's experiences with stigma and discrimination is important to inform interventional policies aimed at encouraging disclosure; enhancing support for HIV infected women and improving adherence to ART among women in this setting. This study explored how stigmatization and disclosure of status influence adherence to ART among HIV positive women.

2. MATERIALS AND METHODS

2.1 Study Design and Setting

This was an exploratory study, which employed qualitative methods to help uncover opinions and gain deeper insight into the problem. The study was conducted from January to June 2012 in the Kumasi metropolis, which is the capital city of the Ashanti region, and the largest of the twenty-seven (27) political divisions in Ashanti Region. It has an estimated population of 1,430,241 with an

annual growth rate of 3.4%. The Ashanti Region has 152 PMTCT centres and 21 ART centers with eight (8) of them in the Kumasi metropolis as at 2011. The prevalence of HIV in the region as at 2013 was 3.2%, second to Eastern region which remains the highest in the country, 3.7% [7].

2.2 Study Population and Sample

The study was conducted in three ART centers across Kumasi. The study population was consenting HIV positive women aged 18 to 49 years who had been put on ARVs for treatment or prophylaxis >3month as well as health workers at the ART center. A random sampling technique was used to select three (3) out of eight (8) health facilities with ART centers, where the study was conducted. These were Suntreso Government Hospital, Aninwaa Medical Centre and Kumasi South Government Hospital. Respondents for the study were sampled purposively. This comprised of 23 HIV positive women who took part in three (3) focus group discussions (FGDs) and 14 health workers who were involved in in-depth interviewing. The purpose of the in-depth interviews was to elicit the views and expert opinions from the health worker perspective whereas the FGDs allowed us to access a broad range of views on the subject matter from the HIV positive women over a short period of time [49]. One FGD was conducted per facility, involving two (2) groups of defaulters and one (1) group of non-defaulters. The health workers involved were HIV counselors (4), Nurses (5), Prescribers (2) and Pharmacists (3).

2.3 Data Collection

Data were obtained through in-depth interviews and FGDs using tape recorders and interview guides. Interviews and discussions were conducted and audiotaped by two researchers, in the local language and were carried out in quiet and discreet locations in the hospital's outpatient department. FGD sessions were carefully prepared by developing key questions based on the objectives of the study. During discussions, the facilitator ensured equal participation and maintained a neutral attitude and appearance. Audio tapes were transcribed verbatim in Twi and then translated into English. Spot checks of interviews, FGD transcripts and translations were conducted by an independent and professional translator to ensure the completeness of the transcription and the accuracy of the translation.

2.4 Statistical Analysis

Data were analyzed thematically with the help of NVIVO software for qualitative research [50]. Interview transcripts were coded according to participants' responses to each question. The most salient emerging themes across the set of focus groups were also identified and coded. Connections between emerging themes were identified and related themes were grouped together according to conceptual similarities and providing each cluster with a descriptive label. A narrative account was made by writing out the themes and exemplifying with extracts from the interviews.

3. RESULTS

The mean age \pm SD of the women involved in the FGDs was 36 ± 7.1 years and their ages ranged from 25 to 49 years. Among respondents who had ever defaulted, reasons cited included having no support, high transport cost, forgot appointment, distance too far, being too sick, not getting money for transportation and lack of privacy at the facility. Respondents cited factors such as to protect baby from infection, to live longer, encouraged by monitor¹ and to prevent becoming bedridden (most cited reason) as reasons for never defaulting ART.

3.1 Stigmatization: People Think anyone who has HIV/AIDS has Committed Adultery

Issues of stigmatization were paramount among the various FGDs. Most of the participants acknowledged that people living with HIV/AIDS are discriminated against in the community because of their status. People, who are afraid of stigma travel long distances to access ART, incur high transport cost. One patient reported that she has to travel from another region to come for the drugs in Kumasi because she doesn't want anybody to see her entering an ART center. This has to do with how people perceive the disease and in many communities in Ghana. One participant revealed;

"People think anybody who has HIV/AIDS has committed adultery or an immorality and

¹ *Supposedly a trusted person a client informs about his/her status and the monitor in turn helps him/her to adhere to treatment regimen. It is an aspect of shared confidentiality aimed at helping clients to adhere to ART.*

so me I don't want anybody to see me at such a place. My brothers and sisters will reject me if they know I have this disease, they will even poison me" (defaulter, 37 years, FGD).

The health workers said during the in-depth interview:

"Because of stigma, some people come from very far places to this hospital instead of going to places near them. So often times, because of the distance, they are not able to honor their appointments" (health worker, nurse, in-depth interview).

"Because of stigma, people find it difficult at times to go to hospitals around them so most people come here from far places so we need expansion. The facility is too small for the number of clients..... and authorities should try and supply all our needs like the drugs and other laboratory machines for the various investigations" (health worker, HIV counsellor, in-depth interview).

The interview with health workers further revealed that follow up on clients in their homes could not be very effective because of stigmatization in various communities. A health worker disclosed:

"We stopped following up because of stigma. If you keep visiting them, people around them will wonder why you keep visiting them" (health worker, HIV counsellor, in-depth interview).

3.2 Status Disclosure Enhances Social Support and Adherence to ART: My Husband Knows My Status Now and He is My Source of Strength

Majority of the participants (86%) had disclosed their status to at least a partner, friend or family member. Disclosure of status was higher among the non-defaulted participants as compared to those who had ever defaulted ART appointment.

Social support was an important factor in ART adherence. Most of the participants who had disclosed their status indicated that they receive some form of support from partner or a family member, whom they have disclosed their status. The forms of support cited by respondents were mainly emotional (encouragement, 41%) and

instrumental support (financial, 35%; escort to facility, 24%).

Some women narrated how they are being supported and assisted when they disclosed their status to their husbands or a family member.

"My husband knows now but I was reluctant to tell him at first and now he is my source of strength. Ever since he knew my status, he has been encouraging me and supporting me in all aspect even though he is negative" (never defaulted, 38years, FGDs).

"Though am not working I don't feel that the transportation or cost of medicines is expensive. I am being taken care of by my brother who knows about my sickness. He encourages me and gives me money for transport and to pay for the drugs" (never defaulted, 45 years, FGDs).

Most of the women who had not disclosed their status had no social support and some of them faced problems accessing ART due to transportation difficulties and inability to afford the cost of drugs. They believed however that they could get support from a family member or partner to cater for these if they had disclosed their status.

A woman narrated:

"[...] I don't always have money for transport and I can't walk too. I don't have any work to do and I don't have anyone to support me. My husband died a year ago. It is very difficult coming here every two weeks for the medicine" (defaulter, 33 years, FGD).

Another participant disclosed;

[...] I didn't have money to pay for the drugs every month. I wasn't paying when I was pregnant but now paying GH¢5 (\$ 2.62 as at December 2012) every month, is very difficult so always have to take them on credit and now I owe so much" (defaulter, 42 years, FGD).

A woman disclosed that she cannot ask for assistance from her husband because he will find out more on why she has to go the facility every month.

"I don't get any support from my husband or anybody because I haven't told anyone

about my HIV status. At times I don't get money for transport but I cannot ask him. This is a shameful disease and I am afraid my husband will divorce me" (defaulter, 37 years, FGD).

An interview with health workers confirmed issues of financial difficulties faced by HIV positive clients, especially among those who have not disclosed their status, as the greatest barrier to ART access.

"Most of the women are paupers and they don't have any support too especially those who have not disclosed their status to any family member. Before they came here they had gone through all those prayer camps, pastors, quack doctors and so on, so before they get here, they have virtually nothing left on them. So if you give them appointment, they will default and come back and tell you, oh I didn't have money for transport" (Health worker, Nurse, in-depth interview).

"We realized that most of them who cannot afford the cost of drugs do default so now we've told them to come for it even when they don't have money so they come and pay later" (health worker, prescriber, in-depth interview).

3.3 Fallouts of Status Disclosure: He doesn't Mind me Anymore, He doesn't even talk to me

Reasons cited for non-disclosure of status included fear of stigma, IPV, neglect, divorce, blame and abandonment. A participant disclosed:

"I have not told my husband because that man I fear him. He will beat me to death if he finds out so I have to give other excuses to be able to come [...]" (defaulter, 39 years, FGD).

Some women narrated the experiences of rejection and IPV after disclosing their status to their partners. Some of the women who have disclosed their status narrated the ordeal they went through after they disclosed their status to their partners. Some of them reported their husbands even left them without a word when they revealed their status to them.

"[...] I brought my husband to check and they said he has not got the disease. He doesn't

mind me anymore; he doesn't even talk to me. He will bring another woman in even if I am around, and sometimes I feel like taking my life [...]" (never defaulted, 42 years, FGDs).

Some women disclosed that they are having unprotected sex with their husbands. They explained that their husbands would become suspicious if they ask them to use condom and they are reluctant to reveal their status to them for fear of divorce and violence.

4. DISCUSSION

The main findings of this study were (i) Disclosure of status enhanced ART adherence among HIV positive women (ii) Fear of stigma, rejection and abandonment prevented some women from disclosing their HIV status and (iii) For some HIV positive women, disclosure of HIV status to a partner lead to IPV, relationship breakups and loss of financial support from partners. Since the inception of HIV/AIDS in Ghana, women have been more affected than men have and the vulnerability to the infection, disparities related to cultural, social and economic status makes women more susceptible to the pandemic. This study has unraveled important issues in status disclosure, stigma and discrimination, social support, which if improved would improve adherence to ART among HIV positive women.

This study found an influence of status disclosure on ART adherence. Women who had disclosed their status narrated receipt of support from their partner or family member whom they disclosed to, and how this helps them to access ART. The support was mainly instrumental support; financial assistance, escort to the family and encouragement. On the other hand, women who had not disclosed their status could not ask for support even when in need and sometimes missed ART appointments because they have not money. Responses from health workers confirmed the difficulty some women face in affording the cost of drugs, which was GH¢5 (\$ 2.62 as at December 2012) in public health facilities but could be as high as GH¢50 (\$26.2) per month in private health facilities [51]. In Ghana, the Ministry of Health through the Ghana Health Service's National AIDS/STI Control Program (NACP) [52] executes HIV programs. The Ministry of Health imports medications for their ART program and controls the distribution to healthcare facilities contracted to prescribe

and/or dispense the medications [52]. The ART services in Ghana is however fraught with drug shortages, a major challenge confronting effective HIV/AIDS treatment across low- and middle-income countries, which hinders adherence to ART [53,54].

This study findings corroborates previous evidence of a positive association between status disclosure, social support and adherence to ART or retention in care among HIV positive women [41,42,55–60]. Disclosure of status open the way to receive support for HIV from family, friends and other support networks and groups [55]. Recognizing the importance of disclosure, the International AIDS Conference, held in South Africa in the year 2000 was themed "Break the Silence", a call on HIV positives to disclose their status [61]. The positive aspects of status disclosure could go beyond assessing support to safer sexual practices among partners [55,62,63].

Status disclosure to a partner is closely linked to partner being tested for HIV [64]. This suggests that women could be more confident to disclose their statuses if they know their partners have tested. The current PMTCT program in Ghana ensures that women are tested once they attend ANC. However, without proper inclusion of male partners, women will still have difficulty with disclosures. Couple counselling and testing should therefore be promoted, with the institution of proper interventional programs to invite the male partners for testing after their partners have tested. Other interventions that improve communication about HIV testing and disclosure among couples and enhance relationship building could also be exploited [57]. This should be accompanied by psychological counselling and support especially in the advent of only one partner being infected, to ensure the support of the other in accessing treatment and care.

Although status disclosure could enhance the chances of one getting support from partner or family, it could also lead to dire consequences that could bare adherence to treatment. HIV status disclosure could be a period of stigmatization, intensified risk for partner stigma and abuse, and in some cases withdrawal of financial support [33]. For many women living with HIV/AIDS, disclosure of status could lead to either an extension of an already existing violence or new conflict especially with HIV screening test [34]. In this study, some women would not disclose their HIV status for fear of

stigma, IPV, neglect, divorce and abandonment. Some women who had disclosed their status to their partners experienced IPV and marital breakups. This corroborates with similar post disclosure IPV, marital separation and break experienced by HIV positive women in other settings, some cases being extreme violence [33,35,65–69]. These fallouts of HIV status disclosure have negative implications for access to ART and retention in care [70–72]. Some women living with HIV travelled long distances to access ART due to fear of being seen and stigmatized, thereby increasing their cost of travel and making it difficult for them to access ART. HIV testing and counselling programs should not force women to disclose but rather provide guidance and strategies to best disclose status to help minimize abuse immediately after disclosure and in the medium to long term.

5. LIMITATIONS OF THE STUDY

This study might have suffered some response bias. It was however presumed that participants were honest and gave answers that were a true reflection of their views and experiences on stigmatization and disclosure of HIV status. Again, interview guides were administered in the local language and some terms might not have been translated appropriately, therefore affecting the study outcome. Authors' ensured double checks after translations to ensure this error is minimized.

6. CONCLUSION

From the study, stigma in the community encourages non-disclosure of status. Non-disclosure of HIV status prevents HIV positive women from getting support from partner or family and lead to defaulting ART appointment. Disclosure on the hand triggers heightened IPV, relationship breakups, and withdrawal of partner support. Some HIV positive women therefore live and have active sexual life with their partners whilst keeping their status from them. Disclosure of status should therefore be handled with caution. There is the need to integrate discussions on risks for partner violence and fear of disclosure into HIV counselling and testing. This will help HIV positive women to develop communication skills in how to disclose their status, and reducing fear about marital separation and break-up. Improving community sensitization on HIV could help to reduce the stigma and encourage HIV positive women to disclose their status. ART has come to stay with

clients testifying to its benefits in keeping them strong and healthy. Consensus efforts must be made to ensure that all barriers to access and adhere to ART are removed to ensure optimal benefit.

DISCLAIMER

This manuscript was presented at the International AIDS conference in Durban, South Africa in 2016.

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ETHICAL APPROVAL AND CONSENT

All authors hereby declare that all protocols have been examined and approved by the appropriate ethics committee and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki. Ethical clearance was obtained from the Committee on Human Research, Publications and Ethics (CHPRE) of the Kwame Nkrumah University of Science and Technology (KNUST) and KATH. Participants signed consent form and had all their concerns and questions answered before data collection began. Interviews were conducted in quiet and enclosed rooms and participants were assured of confidentiality with regard to their data and information.

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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