

TRAUMATIC EXPERIENCES OF WOMEN LIVING WITH HIV/AIDS IN GHANA

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Abstract

Background: Trauma faced by women infected with HIV and AIDS poses great challenge to the coordinated fight against HIV and AIDS. Traumatizing events impacting people living with HIV and AIDS, most notably women, impede diagnosis, prevention and treatment efforts.

Methods: The study set out to investigate the life-threatening experiences of thirty-eight women living with HIV and AIDS in the Lower Manya Krobo District of the Eastern Region, Ghana. The study used focus-groups as method of data collection. The data was analysed through theme identification and grouping, along with selection of relevant quotes.

Results: The study revealed five major life-threatening experiences of the women: disclosure, mental ill-health, isolation, stigmatisation and financial challenges. The study concluded that women living with HIV and AIDS suffer enormous psychological burden of the pandemic in addition to physical challenges. However, it is the social burden of the pandemic that contributes significantly to the eventual death of the victims rather than the disease itself.

Conclusion: Consequently, HIV and AIDS education campaign should be intensified using a variety of media, targeting those social issues identified in this research as part of the efforts to fight the disease.

Key Words: *stigma, discrimination, people living with HIV and AIDS, serostatus, qualitative research.*

Introduction

Since AIDS was initially diagnosed three decades ago, incredible advances have taken place in the understanding, treatment and prevention of Human Immunodeficiency Virus (HIV) disease. In spite of these advancements, HIV continues to ravage the world's population¹. According to the Joint United Nations Programme on HIV/AIDS², an estimated 75.7 million people are living with HIV infection at the end of 2019 compared to other infectious diseases. AIDS was first identified in 1981 among homosexual men and intravenous drug users in New York and California³. Shortly after its detection in the United States, evidence of AIDS epidemics grew among heterosexual men, women, and children in sub-Saharan Africa¹. Ghana's first case was diagnosed in 1986 in Accra⁴ and later spread to other parts of the country.

Since the inception of the epidemic, over 75 million people have been infected and affected with the virus and as at the end of 2019, about 32.7 million have died of AIDS². New HIV infections have reduced by 40% since the peak in 1998, which recorded 2.8 people becoming infected compared to 1.7 million in 2019². Even though new HIV infections are levelling off or even declining in most countries, the virus is spreading rapidly through much of the developing world.

The HIV/AIDS burden on women continues to be a problem globally. The UNAIDS report that every week, around 5500 young women aged between 15-24 years become infected with HIV. In Sub-Saharan Africa, women have been hardest hit as five in six new infections among adolescents aged 15-19 years are among girls. Young women aged 15-24 years are twice as likely to be living with HIV than men². Women and girls accounted for about 48% of all new HIV infections in 2019. However, in sub-Saharan Africa, women and girls accounted for 59% of all new cases in the same year². This means that 59% of women in Africa who are infected are going through various forms of traumatic experiences.

Trauma is considered broadly as "an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being"⁵. Experiences of trauma can have long-lasting impacts on health including but not limited to, complex post-traumatic stress disorder⁶, symptoms of which include re-experiencing trauma, avoiding reminders of trauma, hypervigilance and arousal, negative self-concept, and relationship disturbances. Beyond affecting health, trauma may affect a patient's ability to communicate with and trust providers, and engage in care, which is especially important in HIV treatment⁷. In the United State for example, it is reported that health professionals may stigmatise women and question their decisions to carry pregnancies rather than terminate⁸.

Experiences of trauma in the Ghanaian context, emanate from multiple factors including but not limited to stigmatisation and discrimination. For

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example, pregnant women attending clinic in Ghana are mandated to go through HIV/AIDS test. The outcome of this test can be challenging as this requirement can potentially affect the mental health of these women due to the stigma and discrimination associated with the disease. It is estimated that more than one third (35%) of women around the world have experienced physical and/or sexual violence by an intimate partner or sexual violence by a non-partner at some point in their lives². According to Goffman, stigma is described as an “attribute that is deeply discrediting” imposed by others that reduces a person “from a whole and usual person to a tainted, discounted one” (p.3)⁹. Goffman goes on to say that when this labelling is linked to “discrediting dispositions” it has the tendency to be widely believed in the community¹⁰ which brings about “them” and “us” situation¹¹. Stigma is often associated with discrimination which is explained as an undesirable attribute of an individual which potentially can reduce the person’s status in the eyes of the public⁹. It is also seen as an attribute that links people to undesirable characteristics¹¹. Discriminated individuals are believed to possess some features conveyed as a social identity that is devalued in a particular social context¹².

Fear of stigma impedes prevention efforts, including discussions of safer sex and preventing mother-to-child transmission. People tend to avoid confronting their own risk and adopt preventive behaviour due to the separation between ‘us’ and ‘them’. Utilization of voluntary counselling and HIV testing (VCT) services and disclosure of HIV status are constrained because of the anticipated stigma and the actual experiences of People Living with HIV.

This study sought to explore the traumatic experiences that women living with HIV and AIDS face. It is reported that infected women and girls prefer to seek help from sources other than medical and professional counsellors due to stigma covertly and overtly receive from hospital staff. In some cases, women and girls living with HIV have been rejected by their loved ones and the people in their communities. They have also been treated unfairly in the workplace, and denied access to education and health services in some instances⁹.

Methods

The researcher was interested in obtaining information about the lived experiences of women living with HIV and who make meaning from their conditions hence qualitative research methodology was judged to be appropriate¹³ for this study. This type of research has the ability to find the unique voice within data in order to reach understanding of the participants’ perspectives. The focus of the study was to understand the traumatic challenges women living with HIV go through in the Eastern Region of Ghana. The women recruited for this work were members of an association of people living with HIV/AIDS at the

Manya Krobo District. They meet regularly but for the purpose of data collection, the researcher met them over a six-week period and the six sessions were facilitated by a social worker/counsellor and an HIV peer educator. All study procedures were approved by the institutional review board of the Researcher’s university (Cape Coast University, Cape Coast, Ghana).

Sample

Purposive sampling was used to recruit 38 women from an HIV support group association from the Manya Krobo District. The ages of respondents ranged between 21 to 58 years and had been diagnosed with HIV for an average of 6-years. Twenty-eight participants have had at least secondary education, three junior secondary education and seven had no formal education.

Data Analysis

Data was gathered over six-week period. Discussions from six support group meetings were recorded and transcribed verbatim. The researcher achieved rigour through extended consultations with the participants. Since participants belonged to the same support group association, there were no issues regarding trust building and this relationship ensured deep and rich conversations. Content analysis was performed by reading and rereading transcripts and coding and categorizing phrases or sentences into themes.

Results

HIV Disclosure

The study revealed that disclosure of HIV status by a woman can result in conflict and potentially cause intimate partner violence (IPV). The study participants reported they tried to hide their sero-positive status as far as possible from their partners immediately after diagnosis. To them, they feared being abused or harmed by their loved ones if they were to disclose their HIV status.

A 48-year-old lady puts it succinctly as follows: “my husband was diagnosed first but he did not tell me what was wrong with him. He even hid his medication from me. During this time, I was going through some health challenges so my physician suggested I go through HIV Test. Unfortunately, it came out positive but when I informed him (my husband), he was livid and threw me out of our matrimonial bed”. I slept in the children’s room for most part until my husband passed and the family asked me to vacate the property”.

Another said that her husband’s sisters nearly beat her up claiming she (the wife) had infected their brother. “My only crime was I opened up with one of my in laws whom I trusted and respected”. She gunned up against me with the rest of the family.

Mental Health Issues

In the current study, participants expressed higher levels of psychiatric symptoms which could be interpreted to include depression, anxiety and Posttraumatic Stress Disorder (PTSD) and is consistent with previous studies on trauma and mental health^{14,15}.

A participant had this to say: “following my diagnosis, I was so much afraid and this led me to become reserved. I couldn’t communicate the results to my husband. I lost trust in providers and people in general and I can say this was the most trying period in my life”. I stopped going to church and any other social activity. I was distraught most part of the day and at night, I couldn’t sleep. I also became absent-minded and couldn’t do anything meaningful throughout the day. At a point, I thought I was losing my sanity.

A young unmarried lady recounted: for me, I left for our village for some time but it didn’t help. I tried to relocate to another district to find a job there but when I did, I met someone from my locality who disclosed to my relatives where I was and they came for me. When they found me, I couldn’t tell them what was wrong so they suggested I seek spiritual help. I didn’t know what to say or do at this point because whatever you say or do will confirm their suspicion.

HIV Isolation

Respondents expressed the fear that disclosure of their seropositive status would provide grounds for their spouses to seek divorce.

A 45-year-old mother of six stated that “my husband’s family asked that I leave their son if I have AIDS. Painfully, I got it from him. I left but I couldn’t go with the kids and this has affected my health severely.

Another put it this way: I knew my husband had multiple sexual partners so, when I was diagnosed, I kept it to myself. I feared he will leave me to one of his girlfriends if he was to find out. I couldn’t bear the sight of losing all we have worked for over the years.

Stigmatisation

The study found that people living with HIV and AIDS are at the receiving end of stigma and discrimination. HIV and AIDS stigmatisation and discrimination have been seen all over the world although they manifest themselves differently between countries, religious groups and individuals. They are often seen alongside other forms of stigmatisation and discrimination, such as racism, homophobia or misogyny and can be associated with behaviours often considered socially unacceptable such as prostitution or drug use. Stigma directed at women living with HIV and AIDS not only makes it difficult for them to try to come to terms with and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole¹⁶.

Participants stressed, “people will talk, they will put a label on you. You may be very active working in the community but as soon as you are diagnosed with HIV, you wouldn’t get to serve anymore”. For Asor, a former pupil teacher, the challenge actually came from within. “I know there is stigma attached to the disease but I rather stigmatised myself”. I have not been able to forgive myself from contracting the virus. It has been very hard for me, she added.

Financial Difficulty

The study brought to public view the economic hardship PLWH face resulting from the labelling effect and associated stigma and discrimination attached to the disease.

They see us (members of the HIV/AIDS Association) as people with less value. Others think we are soon to die and don’t deserve to do anything for a living. One reported that she was refused a bank loan to expand her business because someone from the neighbourhood told the loan officer that she was a carrier.

A middle-aged woman said in tears, “I stopped my cooked food business because no one will buy from me for fear of contracting the disease”.

This is consistent with the theme on social isolation and exclusion. The study further highlighted how financial weight on PLWH contributes a significant roadblock to treatment adherence resulting from high costs of medication, transportation to and from treatment centres as well as the opportunity cost of attending clinic.

Discussion

Disclosure: participants in this study preferred not to disclose their HIV status. To them, disclosing one’s seropositive status puts the affected in a challenging and most depressing situation. Majority would prefer non-disclosure to avert the trauma and the stress of telling a loved one. This study is consistent with Okareh and others, who found that among HIV-positive women in Nigeria, thirty-seven per cent of participants reported that disclosure had resulted in partner conflict, and twenty per cent of women reported ongoing conflict or abuse with partners as a result of disclosure¹⁷. Again, a study in Zimbabwe also reported that HIV-positive women experienced higher rates of IPV after disclosure of HIV status than HIV-negative women but both experienced IPV, indicating that disclosure-related IPV is a concern for women regardless of HIV result¹⁸.

Mental Health Issues: The results of the study show that the effects of trauma on women living with HIV go beyond affecting the health of victims but their psychological and emotional well-being as well. The issues regarding trust and confidentiality at health facilities pose great challenges to these women in their bid to avail themselves for treatment, care and support. This is consistent with previous studies^(6,7,8) all

concluding that trauma had debilitating effect on a patient's ability to relate with and trust providers to provide care in a safe and sound atmosphere.

Isolation: HIV infected persons face physical, social, emotional, and economic challenges. However, these challenges have most telling effects on women. This is supported by a study in the United States which reported that women living with HIV have highly disproportionate rates of trauma exposure and recent posttraumatic stress disorder (30%) compared to the general population of women (5.2%)²¹. Social support is critical to the process of dealing with posttraumatic stress, as having others listen, understand, and reflect on an individual's traumatic experience can facilitate the development of new schemas and a revised and meaningful narrative about the trauma¹⁹. The women in this study expressed challenges they have had to endure as a result of their seropositive status. This correlates well with the theme on disclosure. Participants felt they stand to lose already existing relationships if their seropositive status were made known to families and close associates.

Stigmatisation: The women in this study indicated the stress of HIV and AIDS stigmatisation and discrimination. They narrated how stigma and discrimination is seen in their relations with community members, families and work colleagues. This is consistent with Peter Piot's conclusion that when stigma is directed at women living with HIV and AIDS not only does it make it difficult for them to try to come to terms with and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole¹⁶. On a national level, the stigma associated with HIV can deter governments from taking fast, effective action against the epidemic, whilst on a personal level it can make individuals reluctant to access HIV testing, treatment and care. The fears expressed in this study corroborates earlier research on the subject.

Financial Difficulty: Many of the participants in the study reported that one of the most difficult challenges they face as HIV/AIDS victims is financial exclusion. The fear of job loss, divorce by a partner, stigma and discrimination all constitute financial loss. They explained that if people are dissociating from you, you are likely to lose your source of living. Participants' economic status have been negatively impacted. Economic insecurity resulting from stigma and social isolation was challenging to women who had been separated or lost their husbands to AIDS and are themselves HIV positive. This correlates well with Tarakeshwar and Co's²⁰ work which looked at the framework of spiritual coping with respect to cognitive theory of stress in addressing stressors unique to HIV disease. Threat of job loss or loss of a partner was perceived by the participants as highly traumatising and stressful whether perceived or actual.

The women in this study had experienced stress of disclosing their seropositive status, rejection by their loved ones, been divorce and perceived divorce as well as threat of job loss and actual job loss. These experiences, developed in them coping mechanisms such as social isolation (which is self-inflicted), secrecy and denial. Feelings such death, shame and frustration aggravated their self-discrimination. This study showed how trauma impacts the fight against HIV and AIDS. The researcher believes voluntary counselling and testing by professionals would be prompted by a reduction in traumatising events against infected persons.

Conclusion

In this qualitative study, the researcher found that HIV and AIDS related trauma impact negatively towards the coordinated effort directed at treatment, care and support. Understanding the traumatic experiences infected women go through are critical in overcoming the barriers that prevent people from seeking professional help. HIV and AIDS prevention research needs to accept the importance of trauma in HIV response, rather than be coy about it. Such, addressing HIV and AIDS related psycho-social challenges should be at the heart of HIV response, not at the periphery.

Recommendation

In the absence of a supportive legal framework, there is little hope if not impossible to tackle HIV and AIDS-related stigmatization, discrimination and denial. The study revealed that Ghana's efforts at containing the epidemic is not enough to educate people about HIV and AIDS, its mode of transmission or even about legal rights of infected persons. What is missing in the menu of strategies is government anti-discrimination framework supported by a law that will ensure the dignity of infected individual's rights. Such laws must fight popular myths, stereotypes and pronouncements that serve as breeding grounds upon which HIV and AIDS related stigmatisation and discrimination thrive. Again, discriminatory policies need to be developed by government and other employers and enforced to protect the dignity of infected and affected persons. It is important to mention confidentiality and respect for human rights as cardinal principles safeguarding and protecting the rights of people living with HIV and AIDS in Ghana. A more enabling environment needs to be created to increase the visibility of people with HIV and AIDS and to facilitate the formation of support groups so that traumatic experiences emanating from discrimination, stigmatization, and denial can be addressed collectively.

Most importantly, behaviour change communication in the media must focus on changing attitudes through safer sex education and training rather than fear and compulsion. The ultimate objective would be to help people to change their sexual behaviour and the way

the general public respond to those who are already infected with the virus. The importance of the Ghanaian hospitality needs to be emphasised and reinforced.

Finally, the role of traditional leaders and the clergy in bringing about social cohesion must be exploited in dealing with HIV and AIDS related stigmatisation and discrimination. Greater attention needs to be given to the gender-biased nature of HIV and AIDS related traumas. Efforts should be made to address not only women's risks of HIV and AIDS infection but their heightened vulnerability to the social stigma associated with the epidemic. In most Ghanaian societies, there exist a double standard where men are permitted (and even encouraged) to have more than one wife, while women are blamed for the consequences of multiple sexual behaviour. The effects of this double standard on women's health and well-being, property rights and rights of access to children are not healthy and need to be addressed urgently.

References

1. Joint United Nations Programme on HIV/AIDS., World Health Organization. AIDS epidemic update, December 2006. World Health Organization; 2006.
2. *Unaid J*. Fact sheet—latest global and regional statistics on the status of the AIDS epidemic. Geneva: UNAIDS 2020 Jun.
3. Joint United Nations Programme on HIV/AIDS. 2008 report on the global AIDS epidemic. *Unaid*; 2008.
4. Neequaye IE, Neequaye AR, Mingle IA, Ofori-Adjei D, Osei-Kwasi M, Grant F, Hayami M, Ishikawa RJ, Biggar RJ. Sexual habits and social factors in local Ghanaian prostitutes which could affect the spread of Human Immunodeficiency Virus (HIV). *Ghana Med J*. 21:12-15.
5. Substance Abuse and Mental Health Services Administration. (2014). *SAMHSA's Concept of Trauma and Guidance for a Trauma-informed Approach*. HHS Publication No. (SMA) 14-4884. Retrieved from Rockville, MD: Substance Abuse and Mental Health Services Administration:
6. Karatzias, T., Shevlin, M., Fyvie, C., Hyland, P., Efthymiadou, E., Wilson, D., Cloitre, M. (2017). Evidence of distinct profiles of posttraumatic stress disorder (PTSD) and complex posttraumatic stress disorder (CPTSD) based on the new ICD-11 trauma questionnaire (ICD-TQ). *Journal of Affective Disorders*, 207, 181-187.
7. Dawson-Rose, C., Cuca, Y. P., Webel, A. R., Baez, S. S. S., Holzemer, W. L., Rivero-Mendez, M., ... & Reyes, D. (2016). Building trust and relationships between patients and providers: An essential complement to health literacy in HIV care. *Journal of the Association of Nurses in AIDS Care*, 27(5), 574-584.
8. Kirshenbaum, S. B., Hirky, A. E., Correale, J., Goldstein, R. B., Johnson, M. O., Rotheram-Borus, M. J., & Ehrhardt, A. A. (2004). "Throwing the dice": Pregnancy decision-making among HIV-positive women in four U.S. cities. *Perspectives on Sexual and Reproductive Health*, 36, 106–113.
9. Goffman E. *Stigma: notes on the management of spoiled identity*. Englewood Hills, NJ: Prentice Hall; 1963.
10. Ogden J, Nyblade L. *Common at its core: HIV-related stigma across contexts*. Washington, DC: International Center for Research on Women (ICRW); 2005.
11. Reidpath DD, Chan KY. A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*. 2005;17(4):425_32.
12. Padilla, Amado M., and William Perez. "Acculturation, social identity, and social cognition: A new perspective." *Hispanic journal of behavioral sciences* 25.1 (2003): 35-55.
13. Padgett, D. K. (2017). *Qualitative methods in social work research* (3rd ed.). Los Angeles, CA: SAGE.
14. Brown JF. Faith-based mental health education: a service-learning opportunity for nursing students. *J Psychiatr Ment Health Nurs*. 2009; 16:581–8.
15. Hatzenbuehler M. Structural stigma: research evidence and implications for psychological science. *Am Psychol*. 2016; 71:742–51.
16. Piot P. Global AIDS epidemic: time to turn the tide. *Science*. 2000 Jun 23;288(5474):2176-8.3
17. Okareh OT, Akpa OM, Okunlola JO, Okoror TA. Management of conflicts arising from disclosure of HIV status among married women in southwest Nigeria. *Health Care Women Int*. 2015;36(2):149–60. [PubMed] [Google Scholar]
18. Shamu S, Zarowsky C, Shefer T, Temmerman M, Abrahams N. Intimate partner violence after disclosure of HIV test results among pregnant women in Harare, Zimbabwe. *PLoS One*. 2014;9(10): e109447. [PMC free article] [PubMed] [Google Scholar]
19. Kamen, Charles, et al. "The impact of stigma and social support on development of post-traumatic

- growth among persons living with HIV." *Journal of clinical psychology in medical settings* 23.2 (2016): 126-134.
20. Tarakeshwar, Nalini, Michelle J. Pearce, and Kathleen J. Sikkema. "Development and implementation of a spiritual coping group intervention for adults living with HIV/AIDS: A pilot study." *Mental health, religion & culture* 8.3 (2005): 179-190.
21. Machtiger, E. L., Wilson, T. C., Haberer, J. E., & Weiss, D. S. (2012). Psychological trauma and PTSD in HIV-positive women: A meta-analysis. *AIDS & Behavior*, 16(8), 2091–2100.
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