

Sudanese Women Living with HIV/AIDS Stigma and Discrimination

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Abstract

This study aims to explore and describe the meaning and effect of the women's experience of HIV/AIDS stigma and discrimination. The study adopted an exploratory descriptive qualitative research method. The sample is purposefully selected and consists of 10 women living with HIV who were members of people living with HIV/AIDS association in Khartoum State in 2019. Results show that all the participants were facing stigma and discrimination because they were living with HIV and AIDS. Distant relatives were the main source of stigma and discrimination followed by friends' rest of community members. Most participants indicated that they felt they were discriminated because HIV infection is associated with 'sexual misbehavior'. However, some of them complained that they contracted the virus from their married partners and hence they did not deserve to be stigmatized or discriminated against. Results show that there is a need for creation of awareness among community members on the transmission of HIV.

Keywords: Sub Saharan Africa, Women, HIV, AIDS, Discrimination

Introduction

Despite progress in many aspects of the global HIV response, women particularly adolescent girls and young women - continue to be disproportionately affected by HIV. Young women and adolescent girls account for one in every five new HIV infections in Africa and are nearly three times as likely as men of the same age group to be living with HIV in Sub Saharan Africa (UNAIDS2015The Foundation for AIDS Research 2015).

Adolescent girls and young women in sub-Saharan Africa acquire HIV five to seven years earlier than their male peers (Dellar, R.C. et al (2015). Devries, K.M. et al (2013). Stigma and discrimination, as well as inequitable laws and cultural practices, further exacerbate women's vulnerability to HIV and undermine the response to the epidemic (UN women 2015). Recent statistics show that the number of people living with HIV in Sudan have now reached 70,000 people prevalence was at 0.4%. People living with

the disease are the main source through which HIV is spreading. They suffer social stigma and community discrimination (UNAIDS 2013, SNAP 2013). There were 25000 Sudanese Women aged 15 and over living with HIV (UNAIDS 2015). Sudan has one of the largest populations of people living with HIV in Middle-East and North Africa, Sudan is a generally conservative and highly religious society where sexuality is not openly discussed, and a disease such as HIV/AIDS is surrounded by myths and taboos and even ignored in official circles. It is difficult and requires sensitivity to get people to talk openly about the disease (UNAIDS, 2014, WHO 2007). However, the HIV epidemic among Sudanese women exacerbate their vulnerability to stigma and discrimination (Daoud s. 2013). This study gives the chance to five Sudanese women living with HIV to narrate their stories on their stigma and discrimination resulted from being HIV positive.

Objectives of the Study

Describe HIV-related fear, denial and experiences of stigma and discrimination reported among persons diagnosed with HIV

Describe participants' perceptions and understanding of societal and community responses to HIV/AIDS and in particular the role of stigma and discrimination;

Methodology

The study was an exploratory descriptive qualitative research design s used to explore and describe the meaning and effect of the experience of HIV/AIDS stigma and discrimination among ten women living with HIV who were the members of people living with HIV/AIDS association in Khartoum State selected through the convenience purposively sampling process. Using qualitative data collection the women in the sample narrated stories that expressed their emotions, perceptions and experiences of stigma and discrimination resulting from their HIV positive. Collected stories were presented in forms of narrative stories.

Ethical Issues

The researcher obtained permission from the heads of HIV/AIDS Association in Khartoum State . Participation was voluntary and participants were informed that they could withdraw from the study at any time if they wished. Informed consent was obtained from each participant who met the inclusion criteria including the minors where consent was obtained from their parents or guardians before being interviewed. The participants were allocated code numbers instead of names to ensure confidentiality and anonymity results.

Results

Socio-Economic Characteristics of the Respondents

The majority of participants were between 20 and 35 years of age. The youngest participant was 17 years old, and the oldest was 42 years old. Two of women participated on the study were currently single while one was divorced and other two were widow. Two of women completed university education and one was currently university student and two were illiterate. All women interviewed did not born in Khartoum State some of them migrated with their families and other with their husbands from other states in Sudan. Their length of time in Khartoum ranged from three years to 12 years, with an average of 17 years. Three of women interviewed were engaged in small businesses one employed and other was one still student. Two of five women got infected from their husbands while two form sex practices with multiparters and one from blood transformation. The average time since diagnosis was 7 years. Three participants had been diagnosed between 2010 and 20012. All women did not had symptoms of the disease they discovered it by chance

Women's Narratives

This part presents five stories narrated by five women living with HIV. Women narrated in depth their situation, feelings and emotions resulting from being HIV positive

Story One

I am 19 years old university student moved to Khartoum to study. I discovered my infection when donated blood to my friend. I still single got the infection from blood transformation. I feel this is end of the world. I could not tell any one of my family or my friends *stigma would mean that once a person look at me they would just characterize me as sex worker and it is a committed cardinal sin. So that's one of the stigma that will be attached to me being HIV.*

Because they don't know about my HIV status, everybody in the community, they know I'm HIV positive and they talk bad about me. You know, they even call me names. They don't know me, they don't know anything about me, but still, because they found I'm HIV positive, they think I'm a bad lady. Thanks God found some support from the members of association and break my silence but still could not participate on activities conducted by association because I afraid to be identified as HIV positive. I need to be referred and seen regularly by someone who can help me cope with this disease and live with our families and society.

Story Two

I am 40 years old university graduate employed moved to Khartoum for work I got HIV from my husband. Learning that I HIV-positive was one of the most difficult experiences I go through in life. felt scared, sad or even angry. I have been living

without marriage till reached 38 year old but my friends and family pushed me to get married after one year marriage my husband died and discovered my infection I hate the men. I kept my infection secret except told my mother she is giving me support and kindness. Sudanese people discriminate against people living with HIV because *when they hear that someone's HIV positive – they'll be seeing someone who's dying, someone who is not supposed to touch anyone.* "After I was diagnosed I felt so bad and I hated myself but then I calmed down and I joined the association of people living with HIV. Then I felt good and that I accepted my disease as wrath of God. *Association helped me to break the stigma I become active on awareness raising and prevention activities specifically to protect women because HIV stigma affect women more than men. Stigma and discrimination is the biggest problem that we face in our community specially we are women. I got HIV/AIDS from my husband and where he got it, I don't know either; I advise Sudanese girls before marriage should do HIV test.*

Story Three

I still single uneducated, I discovered my infection seven years ago and I got HIV because I used to practice sex with multi sexual partners. I was poor and ignorant of the transmission of HIV. When people discover that I HIV positive, they run away from me and look down to me.

People hate us because the infection of HIV is related to bad sexual practice. I moved from my area to Khartoum the person I would never, ever tell in my life is my mother. You know back home, in rural areas they are highly ignorant of HIV. They don't even believe that there is a way you can manage your life and live longer. Once they hear that someone is HIV positive, the thing that comes into their head is death. I wouldn't want her to know about it – she might die thinking about it." I am happy that the association does not discriminate me instead accommodated and encouraged me got job for me there are some times when it's difficult to cope. But knowing I'm not alone, that there are other people with HIV with similar experiences, and people who'll work on my behalf makes a difference. It gives me the strength to go on to live my life."

Story Four

I am female headed household with many children illiterate and poor. Poverty is the reason that caused to be infected by HIV/ aids because I used to sell my body to support my children. I kept my infection secret inside me my stigma would affect my children

I live very difficult life experience health problems, loneliness, exclusion, poverty and unhappiness. I blame myself for the situation as HIV positive I have to keep all these feelings inside me to survive We feel desperate grief isolated without support. I don't tell people I have HIV because I don't want them to judge me."

My family kept me out of the kitchen and stopped talking to me because I have HIV.

I know I got this through sex. I feel really ashamed having a sexual disease and am no longer interested in having sex." "No one could really want to be with someone who has HIV. "Of course I am afraid for my children. I'm very afraid for their future, and how people will relate to them. 'I do not want any person to know about my disease condition...what people will do for me, I don't want even any physician to know, only my treating physician to know. If others know they will not help me, instead they will blame me and distance themselves away, so I do not want anyone to know my disease condition. The attitude of our society on HIV is very bad. We live in the dark and are scared of the people to know because they will treat us bad and look to us bad

Story Five

I am 45 years I have got HIV from my husband. My husband was abroad for a long time before we got married. I heard he tested positive at that time and was sent back to the country, but he married me without revealing any of this. I have got sick and tested HIV positive my husband and his family divorced me went back to my family a shamed. My husband had gone around telling our previous neighbors about my positive status. I am discriminated against by a lot of friends they afraid to sit near me they treated me like sick animal, because it is assumed that HIV is only transmitted through extra-marital sex and a Muslim woman is not supposed to behave that way. Thus, an additional component of HIV-related stigma could involve the assumption that HIV positive people have transgressed their culture or religion. Some participants indicated that most people do not know about how HIV is transmitted and they fear contracting it through contacts or close association with the PLWHA. There is a lot of inaccurate information about HIV and AIDS on how it is transmitted. People are afraid of contracting the disease, therefore, HIV and AIDS patients are stigmatized and discriminated. "Stigma and discrimination make me feel miserable and sometimes I wish I could die early because I know I am bothering innocent lives. Sometimes I don't want to eat and I know my health is going down slowly". People's feelings toward HIV patients are very bad and they think it is a punishment from God for their sin

Discussion

The stories illustrate what gender reacted stigma means in reality. Many women felt shame low self-esteem due to being HIV-positive. Women was much more likely to have been discriminated against by friends and community members. The stories confirm that attitudes towards people with HIV/AIDS are shaped by the religious, social and cultural framework, and by misconceptions about the methods of HIV transmission among both the general population and healthcare providers (Al-Ghanim, 2005; Badahdah, 2010). This lack of knowledge is significantly and negatively related to stigmatization of people with HIV/AIDS Holzemer W, Human S, Arudo J et al (2009) All participants experienced stigmatization.

Stigma has always been closely associated with HIV/ AIDS (Emlet 2007; Liamputtong et al, 2009; Badahdah and Foote, 2010) Perceived HIV stigma has a significant negative effect on the quality of life of women living with HIV/ AIDS (Greeff et al, 2010)

Sudanese a very conservative HIV/ AIDS is perceived as a moral disease and people with HIV/AIDS are perceived as deviant and as deserving the disease for having violated social and religious rules (Hasnain, 2005). These attitudes are a key factor shaping the lived experience of study participants living with HIV/AIDS in Sudan.

The results that almost all the participants in the study faced some form of stigma and discrimination show a need for community sensitization on HIV and AIDS. Results show that stigma and discrimination should not be ignored or overlooked in the care of HIV and AIDS patients.

Conclusion

It is found that we will never make progress in the response to HIV – prevention, treatment, care or support – unless we deal with the gender dimensions of HIV-related fear and ill-treatment.

It can be said that Stigma can be particularly intense – even overwhelming – for women living with HIV from rural areas, are strongly conservative or religious. Here, women can experience multiple layers of the ‘jigsaw’ of stigma and discrimination. They may be forced into ‘protective silence’ which means that they do not seek support from the community or services,

Recommendations

Young women and girls are not passive victims of HIV-related stigma, but the impact of HIV-positive women’s activism and advocacy needs to be better understood and taken to scale. Indicators that measure stigma need to be tailored to the realities of women’s lives.

Stigma stands in the way of women realizing their rights. So how can progress be made in overcoming this? How can we change people’s attitudes to AIDS? A certain amount can be achieved through the legal process or through institutional and other monitoring mechanisms which can enforce the rights of women living with HIV and provide powerful means of mitigating the worst effects of discrimination and stigma

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