

Dynamics of Stigmatization and Discrimination on Intention to Disclose among PLWHA: A Qualitative Assessment.

Peter O. Olapegba

North West University (Mafikeng), South Africa

hanpet70@yahoo.com

Samuel E. Oladipo

Tai Solarin University of Education

Nigeria

Abstract

UNAIDS (2010) estimated that about 33 million adults are HIV positive, while more than 15 million children worldwide are orphaned by the HIV scourge. Some psychosocial factors contributing to the challenge of combating the HIV phenomenon include stigmatization and discrimination. Research findings have shown that HIV positive individuals are reluctant to disclose their status and access medical care because of the fear of stigmatization and discrimination. Adopting a qualitative approach, this study investigated the dynamics of stigmatization and discrimination on intention to disclose HIV status. In-depth interviews (IDIs) and focus group discussions were conducted. A thematic analysis indicated that there exist stigmatization and discrimination at individual and societal levels against people living with HIV and AIDS, these were as a result of the way HIV and AIDS were represented at the initial stage as a condition that defies any solution. Media representations over time presented HIV and AIDS as dreaded monster that cannot be tamed. Cultural factors also fuel stigmatization and discrimination. Another factor enhancing stigmatization and discrimination is lack of effective policy framework to protect PLWHA from stigmatization and discrimination. It is concluded that stigmatization and discrimination are still prevalent and to combat them there should be effective legislations and enforced policies to protect PLWHA and community-based approach to disseminate appropriate HIV/AIDS knowledge. Also, media adverts should exclude subtle stigmatization representations while cognitive restructuring and attitudinal change programmes should be aggressively embarked upon for the larger society to adopt the right attitude toward PLWHA.

Kew words: HIV/AIDS, disclosure, stigma, discrimination, qualitative

HIV/AIDS pandemic is a global concern that is regarded as a threat to global security in its entire ramification. As far back as 2003, UNESCO estimated people living with the HIV virus to be about 40 million of the world population, without considering those that are affected as caregivers, orphans, widows, widowers and other dependants. Meanwhile, the dialogue on the HIV/AIDS pandemic has gone beyond finding cure, vaccine and ordinary prevention, the last decade has witnessed increase advocacy for a more holistic approach to combat the pandemic and enhance the quality of life of people living with HIV and AIDS. The holistic approach has become pertinent because a significant proportion of PLWHA are in their prime and form the critical mass of the productivity of any country.

UNAIDS (2010) estimated that about 33 million adults are HIV positive while Xu and Wu (2011) reported that more than 15 million children are orphaned by the HIV scourge, these statistics paint a gloomy picture of intervention outcomes over the last two decades. Olapegba (2005) averred that developing countries, particularly sub-Saharan Africa are the worst hit with the HIV scourge. As at year 2000, UNAIDS estimated 23 million people to be living with the condition in Africa, this figure represents 5.5 percent of the global infections. Nigeria, the most populous black nation is said to have the second highest number of HIV infection in the world with a prevalence rate of 4.6 percent (USAID, 2008). The Nigerian Action Committee on AIDS-NACA (2009) reports that 2.95 million people are living with HIV/AIDS in Nigeria, 280, 000 annual AIDS death, over 2.2 million orphaned as a result of AIDS while 380, 000 new infections occur annually.

Owing to the complex nature of HIV/AIDS and the absence of cure and vaccine, research has largely identified that behavioural changes can go a long way in preventing new infections, enhance quality of life of those already infected and thereby act as veritable prevention tool in the fight against the pandemic. Amongst risk factors in the spread of HIV/AIDS and hindrance to effective prevention is non disclosure of HIV status to sexual partners and others that might be at risk by those infected. According to WHO (2004), the prevention and control of HIV infection depends on the success of strategies to prevent new infections and treat currently infected individuals. A major aspect of the strategies is status disclosure among HIV-infected clients, particularly to sexual partners.

If interventions in reducing infections will be effective, then, disclosure must be treated as a public health goal. WHO (year) added that disclosure may motivate sexual partners to seek testing, change behaviour and ultimately decrease transmission of HIV. Besides the benefits of disclosure to sexual partners, the infected individuals also benefit from it in form of increased opportunities for social support, improved access to necessary medical care including antiretroviral treatment, increased opportunities to discuss and implement HIV risk reduction with partners, and increased opportunities to plan for the future.

In spite of the benefits of disclosure both to the infected and the partners, the reality on ground indicate that rate of disclosure is rather low thereby acting as obstacle to prevention initiatives. The disclosure problem is particularly found to be prevalent in the developing countries. WHO (2004) reports that studies in the developed countries show that rates of HIV status disclosure to sexual partners ranged from 42% to 100% while the rates in the developing countries ranged from 16.7% to 86%. Particularly, pregnant

women in antenatal care (ANC) in sub-Saharan Africa reported 16.7% - 32% disclosure rate.

If disclosure will be of immense benefits to the infected, their partners and society at large why then are individuals reluctant to disclose their HIV status? Researchers and practitioners have over the years come up with various factors preventing individuals from disclosing their HIV status; however, stigma and discrimination are two major factors impeding disclosure in both developed and developing nations. The negative roles of stigma and discrimination in the spread of HIV was affirmed by Fredriksson and Kanabus (2005) that ever since scientists first identified HIV and AIDS, the social responses of stigma and discrimination have accompanied the epidemic with unmatched devastation. These social phenomena have fuelled anxiety and prejudice against PLWHA. Infected individuals whose statuses were known were said to have suffered rejection, loss of job, loss of economic power and in some instances the treatment are institutionalized.

Stigma is a powerful discrediting attribute that portrays a person or group in a bad light. Goffman (1963) defined it as an attribute that is deeply discrediting and that reduces a person to one who is in some way tainted and, therefore, can be criticized. Jones, Farina and Hastorf (1984) viewed it as an attribute that links a person to undesirable characteristics that are contrary to the norm of a social group. This indicates that the stigmatized has a social identity that is devalued in a particular social context. Basically, stigma has been associated with diseases that are incurable and severe, and with routes of disease transmission that are associated with individual behaviours, particularly, behaviours that may not conform to social norms (Crandall & Moriarty, 1995). The phenomenon of stigma against people living with HIV often times leads to discrimination. Discrimination refers to a distinction made against a person that results in the person being treated unjustly and unfairly on the basis of his or her belonging to or being perceived as belonging to a particular group. It is composed of actions based on stigma and directed toward the stigmatized. This study looks at how stigma and discrimination influence HIV positive individuals to disclose or not disclose their HIV status.

Problem Statement

UNESCO (2003) confirmed that HIV/AIDS-related stigma and discrimination prevent many PLWHA from seeking treatment and information about the condition. This confirmation is an indication that they are not likely to disclose their status to their partners and others that can be at risk; this definitely has grave consequences for the transmission of the virus. In a similar submission, Settle (2006) added that discrimination and fear are serious obstacles to the design and implementation of effective HIV-prevention programmes. Stigma and discrimination have been reported to be so deep rooted, UNAIDS (2002) reports from a survey that 75% of people sampled in China said they would avoid people infected with HIV/AIDS, and 45% believed that the condition is a consequence of moral degeneration. The percentage may even be higher in Sub-Saharan Africa. Considering the prevalence of HIV-related stigma and discrimination which have persisted over the years, there is the need to investigate factors responsible for the perpetuation of the phenomena against PLWHA which has made disclosure of HIV status a challenge.

Justification

Effective control of HIV/AIDS is a goal that is yet to be attained by Nigeria in spite of the enormity of the problem in the country. There have been reports that people still engage in risk-taking behaviours like multiple sexual partners, casual sex, non usage of condom during intercourse and sharing of sharp piercing objects among others. In addition, there is a report of a rise in national infection prevalence from 4.4 percent in 2005 to 4.6 percent in 2008. Stigma and discrimination have made disclosure a problem among sero positive individuals and this has further fuelled the spread of the virus. The goal of this study is to examine the factors that are sustaining the phenomena of stigma and discrimination and their dynamics, also to investigate how these impinged on the readiness to disclose HIV status. It is to further move the country from a health sector based approach to a multi-sectoral response mode.

Methodology

This is basically a qualitative study to explore the dynamics of stigma and discrimination on the intention of people living with HIV/AIDS to disclose their status. Focus Group Discussions (FGDs), In-depth Interviews (IDIs) and Key-Informant Interviews (KIIs) were used to get the necessary information.

Focus Group Discussions

The participants for the FGDs were recruited through Non Governmental Organizations (NGOs) working with people living with HIV/AIDS. Officials of the NGOs assisted in recruiting the participants who were willing to be part of the study. The purpose of the study was explained to the participants and they were told that they were not under any form of obligation to participate. Those who consented were further informed that they reserve the right to withdraw at any point they feel inclined to do.

In-depth Interviews

Selected participants were interviewed to obtain in-depth information about their experiences and opinion of HIV-related stigma and discrimination as well as intention to disclose status.

Key Informant Interviews

Health professionals, officials of NGOs involved in HIV/AIDS programme, researchers, lawyers and government officials were interviewed on the phenomena of HIV-related stigma and discrimination, how they affect intention to disclose HIV status and how they act as obstacles to developing effective prevention strategies.

Research Instruments

Guides were developed for the FGD, IDI and KII. The interview guides covered knowledge and prevalence of stigma and discrimination and how they influence individual's intention to disclose status. In addition, suggestions as to how to reduce/eliminate stigma and discrimination in order to improve rates of disclosure were solicited.

Data Management and Analysis

The FGD sessions, IDI and KII interviews were recorded using digital audio-recorders. During the sessions, the recorder also noted non verbal behaviour of the participants. The recorded interview sessions were transcribed verbatim, thereafter,

thematic analyses were carried out to identify the major themes from the sessions. The FGDs lasted for an average of 60 minutes while the interviews on the average took 33 minutes.

Result

Stigma, discrimination against HIV-infected persons and intention to disclose status

The focus group discussions, in-depth interviews and key informant interviews brought to the fore factors promoting stigma and discrimination against people living with HIV/AIDS and how these affect intention to disclose status.

There is a general agreement during the sessions that HIV-related stigma and discrimination are still prevalent.

HIV and AIDS are greatly related to promiscuity which our culture is against, those suffering from HIV are seen as deserving of the condition because of their sexual immorality. Even in the hospitals some of the workers do not attend very well to HIV infected persons, they most times treat them with disdain and put them in different wards or buildings.

Some people believe that HIV is a spiritual attack and as such victims should not be allowed to live within the community or live with people that are not infected and because of this people will not want to disclose their status when they found they are positive.

In an environment where sexual chastity is considered a value and religiosity is pervasive it becomes easy for HIV-infected persons to be considered as deserving of what they got and so do not deserve the sympathy of the society, for breaking the norm of sexual chastity or for committing sins against God/gods for which they are suffering the consequence.

Culturally, acceptance of HIV as a manageable condition is low because the initial introduction and media representation is that it is incurable and terrible disease, it used to be called 'arunti o gboogun' (a disease that does not take or respond to medication). Pictures are shown on the television and newspapers of people who look almost as skeletons as how the sufferers will end up like.

The impact of media representation in communication cannot be underestimated, what people see and hear from the mass media influence them to form impression about phenomena. By and large they take such messages as the truth and it may take a long time and lots of efforts to counter such formed opinion or attitude based on the information received. Thus there is need for concerted efforts to repackage media representation of HIV/AIDS as a medical condition and flood the media with more appropriate information about the condition in order to change people's orientations and attitude.

Some of the participants raised the issues of sponsors of the adverts on HIV as militating against acceptability. According to the concern, most of the adverts are sponsored by foreign governments and agencies; this tend to reinforce the belief in some quarters that HIV is a western disease hence, denial sets in.

Disposition of employers is a major reason why people do not want to disclose their status, most employers do not hire HIV infected persons and where the persons is already working they look for a way to sack the person. This is making it difficult for people to disclose their status so that they do not lose their sources of income.

Another participants stated:

You still find people who are looking for job like secretarial jobs, if you come and let them know you are looking for job and you are honest enough to disclose that you are HIV positive, the prospective boss will not take the person

One of the medical doctors interviewed confirmed this fear in the following words:

In the hospital at one time we were telling people don't be afraid. When people come for medical examinations and turn out to be HIV positive and they will be begging us to write HIV negative in the report because they won't get the job. When we tell them there is law to protect them they will say yes it is true but the employers know how to get around the laws.

Another issue that came out of the interview session was that of laws against HIV-related stigma and discrimination. A lawyer has this to say:

There is as at today no federal law on HIV-related stigma and discrimination, it is still in the process of being enacted, in fact it has just passed second reading in the House. The only thing in place now is a working policy that organizations and companies are supposed to observe in matters concerning HIV/AIDS.

A medical doctor also said:

To my knowledge, I don't know of any policy or law on stigma and disclosure in Nigeria. However, I am aware that in England, Europe and the US there are laws that compel HIV positive persons to disclose their status to HIV negative sexual partners before having sex with them. If they fail to do so they are liable to prosecution and jail term if found guilty.

It thus follows that there is an urgent need for appropriate legislation to safeguard the interest of HIV infected persons and the laws when enacted should be adequately implemented such that anyone or organization that violates the law will be appropriately sanctioned. If HIV infected persons are sure of that they will not be discriminated against economically, medically and socially disclosing their status will become less of a problem.

Another factor that came out during the focus group discussions and interviews was HIV knowledge/appropriate information about the condition and mode of transmission. It is generally agreed that many people still do not have appropriate knowledge about the condition, its transmission and management. This ignorance thus fuel stigma and discrimination and prevent infected persons from disclosing their status. One of the participants has this to say:

Education is about knowledge and knowledge they say is empowerment, so if people have knowledge, they will be empowered to do a lot of things. Over the years I think people have not been given enough information or education about HIV/AIDS, how do you contract, how do you care for people living with it and what are the dangers. What dangers will co-habitation with such a person pose to the community or the environment? A lot of this information is lacking. The little people have been able to hear over the radio and watch on television is just what is helping.

Another participant has this to say:

We still have a large percentage of people in this country or community who really don't have enough information, even among the elites – people in academia. So information to me is to take 90% of what really needs to be done on matters of HIV/AIDS in this country.

It is obvious that there is still the need for mass awareness and appropriate education and information dissemination on the issues of HIV/AIDS if stigma and discrimination must reduce or be eliminated. Every stratum of the society should be targeted in this regard, since experience has shown that stigma and discrimination cut across segments of the society.

Findings as well indicate that there are dynamics in the pattern of disclosure among infected persons. A medical doctor in one of the interview sessions said:

The willingness (to disclose) is very low; there is often the request that 'please don't tell anybody'. Many do not want to disclose to their parents, very often they say the parents will not be able to withstand the shock, so they say my father will just collapse and die. Women don't want to disclose to their husband for fear that the husband will chase them out of the home. With men, the disclosure problem is less. Often times, people prefer to disclose to their siblings especially same sex sibling.

Another participant has this to say:

It is easier to disclose to my pastor because he will be able to counsel me and pray for me. I believe my secret is safe with the pastor.

With regards to socio-economic status and disclosure, one of the medical doctors has this to say:

The social and socio-economically solid man in a public position will not disclose to anybody for anything. If in a public position, whether he is in media, or he is in politics and all that, he will not disclose. I have seen some men who literally died in front of my eyes because they refused to disclose. "It is better for me to die than for my career and everything I have worked for to go down, I am finished".

One of the participants said concerning stigma reduction:

This radio jingles, they are impersonal, TV programmes are impersonal. And almost all the time they are sponsored by USA, which again reinforces the whole doubt on this whole message. If we can have a forum where we go to the village Chief and say we want to talk to you about this HIV, can we gather your people? The village Chief understands, we first of all educate him very well and we now call his people, stay under the tree and we talk to them, let them ask questions, answer on and on in their language with our own people, not with any

white man covering anywhere. I think we will be able to get the message across.

Conclusion

This qualitative study revealed a number of important issues regarding stigma and discrimination in relations to intention to disclose HIV status. From the responses, HIV-related stigma and discrimination are still prevalent among the general populace in Nigeria; individuals and institutions still discriminate against HIV infected persons, isolating them, denying them employment and even laying off those in employment. Appropriate information and knowledge about HIV/AIDS and its mode of transmission are still problems in spite of efforts over the years, and these have led to stigmatising and discriminating behaviours which are major challenges to disclosure of HIV status. There is also agreement that media representations of HIV/AIDS especially in the beginning were inappropriate thereby fuelling stigma and discrimination with implication for disclosure by infected persons.

Disclosure of HIV status is still a major problem, most infected persons are very reluctant to disclose their status even to close family members because of fear of rejection, stigma and discrimination. There are obvious cultural beliefs fuelling stigma and discrimination and these are compounded by the lack of enabling national legislation to protect infected persons from any form of stigma and discrimination. In order to stem the tide of HIV-related stigma and discrimination thereby enhancing intention to disclose, dissemination of appropriate knowledge of HIV is imperative, laws must be enacted to protect infected persons while a community-based approach should be adopted to disseminate knowledge, combat stigma and discrimination and encourage disclosure.

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