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# The Experiences and Complexities of Care-Seeking Behavior of People Living with HIV/AIDS: A Qualitative Study in Nigeria

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## 1. Introduction

In 2009, approximately 2.98 million people in Nigeria were living with HIV/AIDS. More than 192,000 deaths were caused by AIDS and 2.175 million AIDS orphans are now living in Nigeria (UNAIDS, 2010). The availability of anti-retroviral therapy (ART) implies that people living with HIV/AIDS (PLWHA) should be able to carry out daily activities like the rest of society. However, there are a number of hindrances to the utilization of care, leading to suboptimal effectiveness of available treatment (Hilhorst et al., 2006; Morolake et al., 2009). One of the factors seems to be stigma; PLWHA and their care givers have to cope with negative reactions from the people directly around them as well as from the community (Mwinituo & Mill, 2006; Mitchell et al., 2007; Sabin et al., 2008; Adewuya et al., 2009; Hejoaka, 2009; Demmer, 2011). A study carried out among home based care givers in KwaZulu Natal South Africa showed that home based care givers experience high levels of burden and are targets of HIV-related prejudice and discrimination (Singh et al., 2011).

Not only does the discovery that one is infected with HIV lead to fear of progression into AIDS and fear of dying, it also creates an anticipation of negative social reactions among PLWHA. Sontag (1989) argues that it is not the suffering of the disease that is deeply feared, but the denigration that is suffered from having the disease that makes PLWHA vulnerable as individuals and within society. People in the community have a negative attitude towards PLWHA because they attribute the characteristic of promiscuity to those who are infected (Campbell et al., 2007). Societal norms and values in Nigeria are restrictive and secretive, while discussion about sex is often private for cultural and religious reasons (Ajuwon et al., 1998), making people who transgress these norms likely to be condemned because norms are very strong and strict.

Several studies around the world (Amirkhanian et al., 2003; Singh et al., 2009; Stevelink et al., 2011; Vlassoff & Ali, 2011) and in Africa indicate that PLWHA are still discriminated against (Muyinda et al., 1997; Duffy, 2005; Shisana et al., 2005; Muula & Mfutso-Bengo, 2005; Hilhorst et al., 2006; Liamputtong et al., 2009; Morolake et al., 2009; Amuri et al., 2011), making them resort to varied ways of coping with their problems (Mbonu et al., 2009). Despite these studies indicating the presence of stigma, literature have equally acknowledged that one of the positive noticeable interventions in the fight of HIV/AIDS

and stigma is giving HIV/AIDS a human face (Fokolade et al., 2009; Morolake et al., 2009) but this implies that PLWHA who are active in public HIV/AIDS programmes may have to cope with additional problems. A UNAIDS summary of literature on HIV-related stigma and discrimination recognizes the strengthening of networks of PLWHA that take lead in addressing stigma and calls for more studies to evaluate stigma and discrimination programs (UNAIDS, 2009; UNAIDS, 2010). There is an urgent need for evidence-based research to meet the needs of those affected by HIV/AIDS (Doyal, 2009). Moreover, experiences of PLWHA who are members of an existing network will help in future HIV/AIDS policies that can be used in society and by health care institutions (Nyblade et al., 2009).

In this chapter, we aim to report results from a qualitative study that explores the stigmatization experiences, coping mechanisms and care-seeking choices of PLWHA who belong to an association network in Port Harcourt, Nigeria. We also explore the possible role of contextual factors related to these stigmatization experiences and the PLWHA's health care-seeking behavior as a consequence.

## 2.Theoretical framework

Following prior research on stigma in relation to HIV/AIDS (Mbonu, Van Den Borne & De Vries, 2009), using an inductive approach from an extensive literature review in Sub-Saharan Africa, we adapted the Precede portion of the Precede-Proceed model (Green & Kreuter, 1999) as an explanatory model. The PRECEDE-PROCEED model provides a systematic approach for assessing quality-of-life of health and for designing, implementing, and evaluating health education and health promotion programs. PRECEDE includes five phases. In phase 1, quality of life or social problems and needs of a population are identified. Phase 2 includes an epidemiological analysis in which the relevant health problems are identified. Phase 3 involves an analysis of the behavioral and environmental determinants of a key health problem. In the fourth phase, the factors that predispose (beliefs, knowledge, self-efficacy, social norms, etc.), reinforce (e.g. social support), and enable (facilities etc.) the health behavior, are identified. In phase 5, the focus is on the development of a health education or health promotion intervention that would encourage desired behavior change, changes in the environment, and changes in the determinants of behavior and environmental factors. PROCEED includes an implementation phase, an intervention process evaluation, impact evaluation of changes in behavior or environment, and an outcome evaluation in which the impact on health and quality of life is assessed (Green & Kreuter, 1999). Since models are constantly modified to fit the situation (Chiang et al., 2003), we specified the model to the health care-seeking behaviour among PLWHA and used it to analyse people's coping strategies in dealing with stigma-related problems (Mbonu et al., 2009). The model proposes that a complex health problem, such as care-seeking behaviour of PLWHA, is a function of various factors; and these factors have to be considered from a wider perspective of the social structural context.

The first component of the explanatory model is the analysis of the problem – that is, care-seeking behaviour of PLWHA and how stigma influences it (see [a] in Figure 1) and how it may have an impact on the socio-structural context within which PLWHA, society and healthcare professionals are embedded. The second component of the model involves identifying the predisposing, reinforcing and enabling factors. The predisposing factors are represented as variables such as beliefs, knowledge about HIV transmission and self-

efficacy. Reinforcing and enabling factors are represented as moderating variables, such as poverty, gender, age, religion and policy and how stigma may impact on the variables that determine individuals’ care-seeking behaviour. The model finally specifies different coping strategies (coping with self, coping directed at others and comparison with others, coping with solving the problems of HIV/AIDS) that can lead to various care-seeking choices, such as inappropriate self-care, inconsistent use of biochemical care or use of traditional healers and faith houses, which may result in non-utilisation of healthcare institutions. In our explanatory model, non-utilisation of healthcare institutions is the outcome variable (see [n] in Figure 1).

In this study, while the interview was left open for interviewees to express a variety of issues, thoughts and feelings with respect to stigma and other concepts, we use the explanatory model as a general framework for identifying relevant categories of variables.

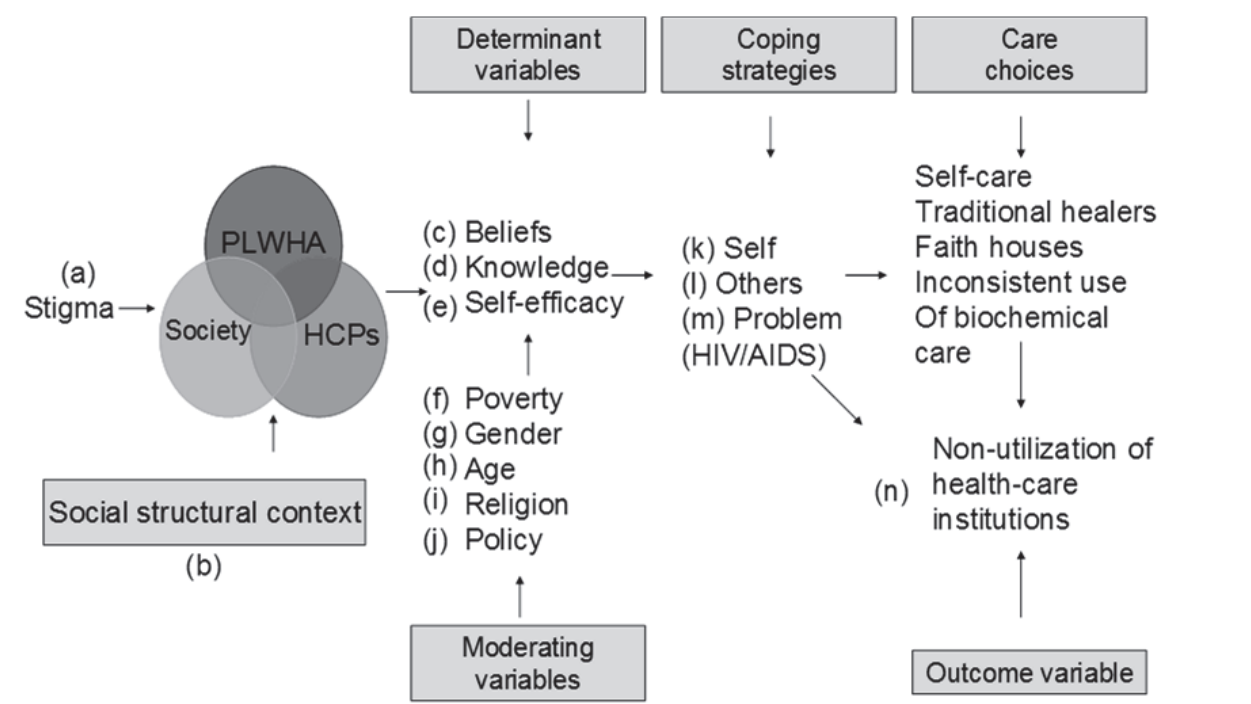


Fig. 1. Explanatory model of role of stigma in care-seeking behaviour.  
Mbonu, Van den Borne, & De Vries, 2009

### 3. Methodology

We conducted in-depth semi-structured interviews with a purposive sample of 20 adults (12 females and 8 males) living with HIV/AIDS who were receiving care from a resource centre in Port Harcourt, Nigeria. Participants are members of network association of PLWHA and therefore were willing to be interviewed about their circumstances. All persons approached agreed to participate. Participants identified themselves as Christians and their ages ranged from 24 years to 48 years. In addition, ten of these participants (6 females and 4 males) participated in a focus group discussion which was conducted in the resource centre. The focus group discussion allowed the participants to exchange ideas and react to issues brought up by fellow participants. The resource centre was established to care for PLWHA and people with other sexually transmitted diseases. In addition, it provides pre and post HIV test counseling and nutritional advice for the PLWHA. Informed consent was obtained

verbally from the persons who were interviewed and their anonymity was guaranteed. The aim of the study was explained to them before the interview took place. Interviews were conducted in the English language. Rivers State Agency for the control of AIDS approved the study.

The interviews were held in the resource centre or, in some cases, in people’s residences (3 people). All the participants discussed freely the questions and issues covered in the study. The interviews were transcribed from audio tape and analyzed. The software package Nvivo 7 was used to analyze the data and identify major themes from Figure 1. Coding was done by the first author and subsequently validated by an independent researcher, who coded a random selection of data to look for new concepts. Emerging themes were compared by the independent researcher with the coding by the author. New entries and discrepancies were checked by re-reading the transcripts and fine-tuning interpretations until unambiguous categories and themes were agreed.

Table 1 shows information about the participants

Nr.	Gender	Status	Work	Reason for HIV test	Age	ART status
1	Female	Widow	Government Worker	went for test after the Husband was sick with HIV	40 years	On ART
2	Female	Widow	Government Worker	went for test after the Husband was sick with HIV	44 years	On ART
3	Female	Single	Office Worker in Company now unemployed	was sick and went for test afterwards	24 years	Not yet On ART because of lack of Money
4	Female	Single	Company Worker	was sick and was sent for testing	39 years	On ART
5	Female	Widow	Government Worker	went for test after the husband was dying From HIV	45 years	On ART
6	Male	Single	Private Office Worker	sent for test after being sick	35 years	Take herbs, Fruit, and Vegetable he stopped ART Reacts to ART
7	Female	Married	Housewife (husband lost job)	discovered HIV status during delivery of baby	29 years	On ART
8	Female	Married	Housewife	Discovered HIV status during delivery of baby	27 years	On ART
9	Female	Widow	Petty trader	went for test after husband died from HIV/AIDS	38 years	On ART



Nr.	Gender	Status	Work	Reason for HIV test	Age	ART status
10	Male	Separated	Government Worker	sent for test after sickness	41 years	On ART
11	Female	Married	Unemployed	went for test during delivery	29 years	On ART
12	Female	Widow	Government Worker	Pre-operative test screening	45 years	On ART
13	Female	Widow	Secretary (lost job)	Got sick and sent for test	40 years	On ART
14	Female	Married	Company worker	Got sick and sent for test	48 years	On ART
15	Male	Single	Banker	Got sick and sent for test	40 years	On ART
16	Male	Married	Government worker	Got sick and tested	38 years	On ART
17	Female	Widow	Petty trader	Husband was sick	47 years	On ART
18	Male	Single	Government worker	Was sick and went for test	28 years	On ART
19	Male	Single	Company worker (lost job)	Company screening	35 years	On ART
20	Male	Married	Unemployed	Was sick and tested	29 years	On ART

4. Results

The results of this study are organized according to the components of the explanatory model in Figure 1. Some basic distinguishing characteristics of participants are provided after the quote.

4.1 Stigma

Participants indicated that negative reactions towards them were the major problems they had, affecting the way they cope with HIV/AIDS and leading to non-utilization of health-care institutions. These negative reactions came from the community, including their close social networks, such as neighbors, family or their spouse. A participant explained the reaction of her neighbors when they discovered the positive status of her and her husband: *‘My neighbors found out in the church that my husband and I are HIV positive, they now pursued [sic] (sent away) us from the compound. The landlord and the neighbors drove us away from the compound we are living in because they said HIV will affect them. We live in an uncompleted building now.’ (Female, 29 years, housewife, participant 7, in-depth interview)*

Some participants, even without revealing their HIV status to their partners, were abandoned because of suspicions of being HIV-infected. Others lived with their spouses although these spouses knew they were HIV-positive. But anticipated public reactions are apparently strong. A participant in the focus group discussion reported being abandoned by her partner when she went public with her positive status: *‘I have lived with this man for five years. I have had HIV since then but he accepted it. He even was planning to marry me but then I went on a programme on the radio and his friends recognized my*

*voice. They immediately called him and after that he left me because he said he was ready to live with the knowledge of my HIV alone but not to share it with others. I find it stupid because he has lived with me all this long.'* (Female, single, company worker, FGD)

This has implications for seeking care at health-care institutions if the participant needs her partner for financial support. Furthermore, some participants reported that health-care professionals (HCPs) also exhibit negative reactions towards PLWHA. The negative reactions from HCPs were enough to discourage them from going for treatment, leading to non-utilization of health-care institutions, as illustrated by these quotes:

*'Some health care professionals are not friendly when they come to find out that someone is HIV-positive. They tend to discard [sic] someone. They will not attend to me in the clinic and ask me to wait by the corner while attending to others.'* (Male, 41 years, separated, government worker, participant 10, in-depth interview)

*'Before, I had a problem with health-care professionals in the hospital where I delivered my baby, they were not nice. It was there I found out my HIV status. They started running and avoiding me.'* (Female, 29 years, housewife, participant 11, in-depth interview)

## 4.2 Determinant variables

The model also postulates that stigma has impact on three kinds of variables (beliefs, knowledge about HIV/AIDS, and self-efficacy) which are particularly important because of their impact on the coping strategies that PLWHA use and on the health-care choices they make leading to non-utilization of health care facilities.

### 4.2.1 Beliefs

Beliefs (see [c] in Figure 1) can either be general beliefs about HIV infection or about persons with HIV or AIDS, e.g the pathways of HIV infection. The following quotes illustrate this:

*'I think HIV is a problem for everyone who has HIV because the society thinks you are loose [sic] promiscuous.'* (Male, 35 years, single, company worker, participant 6, in-depth interview)

*'People will blame me for having HIV because they will say I am a prostitute.'* (Female, 24 years, single, unemployed, participant 3, in-depth interview)

The anticipation of reactions based on these popular beliefs makes PLWHA refrain from seeking care. It can also be beliefs about the reactions of others to the care-seeking behaviour of persons with HIV or AIDS, or specific beliefs about the feasibility of coping. This can lead to the non-utilization of health-care institutions and thereby make PLWHA unable to get the quality of care they need. Apparently, the expectation is that society will label every PLWHA as promiscuous and irresponsible. PLWHA are very aware of these societal beliefs. They expect to be blamed. As one participant said frankly to the interviewer:

*'You should campaign more to people. You should tell people it is not only by sex that people have HIV, which is always the problem. When people change towards people with HIV then we can get better support and care at home and hospital.'* (Female, 45 years, widow, government worker, participant 12, in-depth interview)

### 4.2.2 Knowledge

This can be knowledge about HIV and AIDS (see [d] in Figure 1), HIV status, HIV transmission and about effective treatment, which are important for the utilization of health-care institutions. In our study, all of the participants were aware of their HIV status and antiretroviral therapy (ART) because they belonged to an association network. In the general population, knowledge is expected to be limited. Furthermore, many of the

participants felt that joining an association of people in the same situation helped them gain knowledge of HIV/AIDS and its care possibilities, for instance:

*'Persons with HIV should join the association of people living with HIV and AIDS so they can get good information about the disease.'* (Female, 40 years, widow, government worker, participant 1, in-depth interview)

#### 4.2.3 Self-efficacy

Self-efficacy (see [e] in Figure 1) is the idea that one can carry out a task effectively and leads to problem-focused coping such as PLWHA finding the right health-care institution and the right treatment from health-care workers, going for HIV tests, or handling their condition and situation if others know about their HIV-positive status. Some of our participants had adequate self-efficacy in handling the situation when their HIV status was revealed to their relatives. For instance, a participant who is on ART described how he handled the situation with his brother when he disclosed his positive HIV status this way:

*'My brother wanted to withdraw from me but when I talked to him, he understood ..I told him it can happen to even him, beside he has seen that I am not dying and I am still going on with my life.'* (Male, 41 years, separated, government worker, participant 10, in-depth interview)

A few others had low self-efficacy in handling their situation when others heard about their HIV status. Some participants who looked at HIV/AIDS as a chronic illness felt more confident in handling their situation of being drug-compliant and going for treatment at hospitals. One participant explained that normally in society, one is expected not to talk about one's illness and HIV/AIDS is no different, so, based on this expectation she decided to keep it a secret from others that she was taking her ART medications:

*'It is not only people with HIV that take drugs, hypertensive people take drugs, diabetes people take drugs and still these sicknesses do not go.'* (Female, 40 years, widow, company worker, participant 13, in-depth interview)

By implication, the strong stigma around HIV inhibits high self-efficacy. PLWHA seem to regard HIV/AIDS as just another illness as a psychological means to increase their confidence in handling problems associated with HIV/AIDS and its care.

#### 4.3 Moderating variables

The model also postulates that certain moderating variables (poverty, gender, age, religion and policy) have an impact on the coping and care-seeking behavior of PLWHA.

##### 4.3.1 Poverty

Our participants reported that although many of them are aware of the benefits of ART, many are unable to utilize the health-care institutions and take ART because they do not have the money to procure it or pay for other medical and laboratory costs. Some, who do buy ART, are unable to routinely take their medication due to lack of money since many of them lost their jobs after HIV diagnosis. Participants were also concerned about how their financial problems affect the whole family. For instance, a participant explained her dilemma in going for treatment:

*'I have not gone for treatment because I do not have money. I need money. I am broke. I have to feed myself. Right now, my husband is admitted in the ward. Even I have lab test to do but I have no money. I need money to buy food, drugs. My child is sick too with HIV.'* (Female, 29 years, housewife, participant 7, in-depth interview)

Further discussion showed the difficulty with utilization of health-care institutions:



*'In our organization, people living with HIV/AIDS are facing a lot of problems. Most of them are not working. Some of them were working before but because of their HIV status they were laid off from their work. Many of them are jobless that is why treatment is difficult. We lose our members often.'* (Male, 41 years, separated, government worker, participant 10, in-depth interview)

#### 4.3.2 Gender

Our study shows that due to stigma associated with HIV/AIDS, male PLWHA are not willing to disclose their positive HIV status to their wives causing delay in seeking care. There seems to be a clear difference in the timing of HIV/AIDS diagnosis between male and female participants. Women find out much later after being infected. There are a number of reasons for this. First, society expects women to be conservative and faithful to their partners; such cautiousness, however, does not protect women from HIV if their partners keep multiple partners and do not use protection during sexual intercourse. Moreover, even when women find out their HIV status, they have to disclose to their partners immediately if they want to secure financial aid for treatment. On the contrary, society tolerates men with multiple partners. Men who are HIV positive may still be angry when they find out and blame women for their HIV infection. In this study, married women, who contracted HIV from their partners, felt very bad and betrayed when they discovered their positive HIV status. Two of the female participants in particular (participant 1 and 5) expressed anger towards their partners because of assumed infidelity resulting in infection:

*'The thing (HIV/AIDS) pains me (very angry). I married him as a virgin, I never played life. The thing pains me. You know if I played life as a young girl, I would feel better but I tell you, the thing pains me.'* (Female, 45 years, widow, company worker, participant 5, in-depth interview)

Another said:

*'I was very sad and confused. I now understand why my last three children died. When I was pregnant with them my pregnancy was not even up to nine months and they did not grow well like my first three children. They were always emaciated. They were premature and this man (her husband) knew he was HIV-positive and did not tell me. It is bad.'* (Female, 40 years, widow, government worker, participant 1, in-depth interview)

Second, men take decisions in the family and are breadwinners while women are mostly dependent. These differences are shown at the diagnostic and during illness phases. At the diagnostic phase, some women in this study were diagnosed as part of routine blood tests at pregnancy. This led to women discovering their HIV status without being previously informed by their spouses. At the illness phase, some women in this study were ill but needed their partners' support and approval before seeking care. Women who are tested during pregnancy find out earlier in contrast to women who present themselves to the hospital for an HIV-related illness. Apparently, the male control and lack of support hinders women from making early effective care choices such as VCT. On the contrary, males cannot be diagnosed routinely because they are never pregnant. Male participants presented themselves with illness to the hospital before being sent for HIV test and did not need approval from their spouses before seeking care. An early diagnosis is important because when people find out their HIV status early, they are more likely to make an effective care choice especially for those who know about ART. Female participants emphasized their frustration at the lack of knowledge of their spouses' HIV status. This female participant put it this way:

*'Imagine how my husband hid his HIV status from me so I now have HIV/AIDS from him. If I was a man, I would not be in this condition because I know myself.'* (Female, 40 years, widow, government worker, participant 1, in-depth interview)

In summary, the gender issue is relevant in care seeking because it affects time of diagnosis, societal blame and necessity of disclosure to partner.

#### 4.3.3 Age

Our study shows that young participants emphasized a strong interest in marrying and having children. This was particularly important for them to fulfill their societal role. The emphasis on reproduction was demonstrated by this participant:

*'Infact this baby issue has given me a lot of stress. You know, I have to think of the uncertainties.'* (Male, 35 years, single, company worker, participant 6, in-depth interview)

They believed that the ART will prevent their babies from being infected with HIV. This encouraged them to seek access to ART and care despite the costs involved in accessing care:

*'I plan to have a baby because I do not have any. HIV will not affect my baby again provided I am taking my Anti retroviral therapy drugs.'* (Female, 29 years, housewife, participant 11, in-depth interview)

*'I will like to have baby. I am looking forward to marriage. My unborn baby maybe infected but we are told in the hospital that if you take your drugs effectively the baby may not be infected.'* (Male, 41 years, separated, Government worker, participant 10, in-depth interview)

On the contrary, due to fear of stigma young people may not want to go for HIV testing. This enhances the spread of HIV/AIDS and decreases prevention of vertical transmission. This participant who disclosed his positive HIV status to his girl friend found it difficult to convince her to go for HIV testing:

*'I tried to encourage my girlfriend to go for HIV test but she did not agree to go for the HIV test. I gave her some money but she will turn and ask me whether she is sick? Why should she go for test? I told her it is important she goes for the test because I have the feeling that she has HIV because if she does not get it from me then she may get it from another person. She was angry with me that I am accusing her. At the end of the day she did not go for the test before we parted.'* (Male, 28 years, single, government worker, participant 18, in-depth interview)

#### 4.3.4 Religion

Our data show that some participants received spiritual and psychological support from the pastors in the church; however, the church congregation is not free from stigmatizing reactions. Since the church is made up of members of society, in further anticipation of gossip, this participant indicated a lack of trust in people at his church:

*'In the church where I go, the moment they know my HIV status, they will start asking each other whether they have heard? It is even your closest friend that will give you out.'* (Male, 48years, married, company worker, participant 14, in-depth interview)

Such anticipations of negative reactions of church members can discourage PLWHA from utilizing health-care institutions. This may also lead to not looking for and not getting support from relevant others.

#### 4.3.5 Policy

Discussion with participants revealed that many of them wanted free anti-retroviral therapy and wanted the government to implement a policy for protected work and a financial policy for PLWHA such as provision of micro-credits, which would enable them to pay for health-care facilities. A participant said this:

*'Government should come to our aid. They should give us work because many of us whose HIV status is known have lost their job. They should give us micro credit.'* (Female, 40 years, widow, government worker, participant 1, in-depth interview)

At the time this study was carried, participants had access to subsidized ART, which means they still have to pay some expenses out of pocket which some of them could not afford. All the participants in this study went for HIV diagnosis with a clear reason. 5 women were tested after their husbands were sick or dying from HIV/AIDS, 3 women were tested during antenatal care, 4 women and 7 men were tested because of illness, and 1 man was tested at the behest of employers. Further discussion revealed that some employers send people for compulsory HIV testing without pre-informing them about the HIV test; afterwards they fire staff with a positive HIV diagnosis. A participant in the focus group discussion said this:

*'What happens here is that immediately a company discovers one is HIV-positive, they will not terminate the appointment based on HIV. It will not be written in one's letter. They may say because of so much labor they want to downsize the company. I lost my job. The company had to go through HIV screening test. All the staff was involved. After discovering that some of us were HIV-positive, they had to lay us off. They did not call it HIV test, they called the test a different name because they know if they call it HIV test some people will not go for it. In the process some of us were affected and I am one of those people affected.'* (FGD)

#### 4.4 Coping mechanisms

In the following section, we report how PLWHA cope with HIV/AIDS and how different coping strategies affect PLWHA utilizing health-care institutions.

##### 4.4.1 Coping with emotions because of HIV/AIDS

As shown in (k) of Figure 1, PLWHA may use different internal coping strategies directed at their own emotional problems. Some of our participants showed some fearful emotional reactions after diagnosis, such as thoughts of suicide and feelings that society would not show them sympathy if they knew about their positive status. A male participant reacted to the diagnosis like this:

*'Initially, I felt very bad when I knew of my HIV status. I thought myself has finished in this world.'* (Male, 41 years, separated, government worker, participant 10, in-depth interview)

A reaction from another participant was more extreme:

*'I was scared when I was told I have HIV/AIDS. I felt like killing myself.'* (Female, 24 years, single, unemployed, participant 3, in-depth interview)

The study's participants tried to cope with these emotional reactions through denial or by downplaying HIV/AIDS as a serious threat. They compared HIV/AIDS with other illnesses, denying that HIV/AIDS was any serious threat and that helped them to cope. Furthermore, they rather emphasized that HIV is not contracted from sex alone for example:

*'HIV/AIDS is a normal sickness and anybody can have it, it can come by sex, sickness or even the Hausa people (some Northern people) that move around doing pedicure for people.'* (Female, 40 years, widow, company worker, participant 13, in-depth interview)

##### 4.4.2 Coping directed at others and comparison with others

Second, the coping strategy of PLWHA aimed at reducing the unfavorable reactions of others (see [l] in Figure 1) may include hiding tendencies, finding support from significant others or comparison with other people living with HIV/AIDS. This strategy may also involve trying to influence the meaning other people attach to HIV and AIDS (Goffman,

1963), such as attributing their HIV/AIDS to poison. Our study showed that the feasibility of hiding their HIV statuses depended on the stage of illness and use of ART. The concealment of their positive status enabled them to carry out their activities. In the focus group discussion, many participants explained why ART helped them cope with the physical features associated with HIV/AIDS. Many felt better with ART and did not have the look typical of AIDS patients, for instance:

*'Since I started taking antiretroviral therapy, people do not know I have HIV/AIDS. They cannot suspect.'* (Female, married, company worker, FGD)

Another way of coping reported by the participants was to withdraw from people who they thought may suspect or know their diagnosis. They resolved not to tell anybody, as illustrated by the following quotes:

*'I have not told any other person. I did not tell my friends, If I tell them, na dey same thing [sic] (the same thing), they will run away from me.'* (Female, 29 years, housewife, participant 7, in-depth interview)

*'The society will not welcome me when they know my HIV status, so it is good keeping it to me instead of people running away from me. That alone can cause emotional stress to me. It can cause more problems to me when I am rejected.'* (Male, 48 years, married, company worker, participant 14, in-depth interview)

Some of the participants chose to use selective disclosure. Selective disclosure was commonly made to people they trusted and who could support them:

*'I told my girlfriend who is also HIV positive but we did not know before we met. I told my doctor and my God. I told my doctor because I need his advice. HIV is something between the person, his or her doctor and God.'* (Male, 35 years, single, company worker, participant 6, in-depth interview)

*'I told my husband, two of his sisters and one of my pastors. I told them because they are close to me.'* (Female, 27 years, housewife, participant 8, in-depth interview)

Disclosure continues to be a huge problem. A few participants disclosed their status involuntarily out of necessity for financial support; while for some participants, people around them just ended up knowing. Some tried to deny it even when confronted. A participant, who discussed his positive HIV status on TV, still hides from his neighbors. He tries to deceive them into believing he is just working for an organization:

*'I do not keep my HIV status quiet but I tend to keep it quiet within my vicinity; but outside my vicinity I expose it because they used to call me out for programme. My neighbors used to say they saw me on the television but I always tell them to confuse them that we have an organization or I belong to an organization that take care of people with HIV and AIDS.'* (Male, 41 years, separated, government worker, participant 10, in-depth interview)

Others decided not to tell their colleagues because they did not want to lose their jobs. Concealment may be necessary for them to keep up with their financial obligations that would enable PLWHA utilize health-care facilities. This participant said the following when asked whether any of her colleagues knew about her positive status:

*'Ah no... (Laughter). I have to tell you the truth, they [colleagues] will not mind to sum up one thing and that will be the reason for sending me out of the job. I will therefore tell nobody.'* (Female, 40 years, widow, government worker, participant 1, in-depth interview)

Disclosing HIV status to children was particularly difficult due to what is widely believed to be the cause of HIV/AIDS and fear of losing role model status. Sometimes, PLWHA preferred to wait until they were actually sick with HIV. Another problem that PLWHA tried to cope with was with significant others such as their partners. Some of them had got married without informing their partners until pregnancy, while others hoped their ART



would help when they get married. This has implications for the spread of the virus, as well as for the process of seeking appropriate care at an early stage. Many PLWHA felt it was difficult to give an explanation for being unfit to have children. On the contrary, a female participant who was already married and felt she had contracted HIV through a blood transfusion during childbirth received positive support from her spouse. PLWHA may also prefer to associate with other people with HIV/AIDS by joining association networks as a way of coping with their illness. Others simply ascribe HIV/AIDS to another, more acceptable cause, such as attributing HIV/AIDS to poison, which may encourage them to use traditional healers and prevent them from utilizing health-care institutions. For instance, the husband of this female participant who was HIV-positive said he was poisoned:

*'This man (my husband) knew he was HIV-positive and did not tell me. It is bad. He told me his village people (his kindred) gave him juju (African charm/poison).'* (Female, 40 years, widow, government worker, participant 1, in-depth interview)

#### 4.4.3 Coping directed at problem solving

Third, to solve this problem related to HIV/AIDS, some participants reported strategies that excluded going to the hospital early and consistent use of ART (which are known to be effective). Instead, they preferred to try other options first rather than going to hospital for treatment with ART. Many of the participants mentioned using a combination of therapies; they went to faith houses, traditional healers, used herbs or combined them with attending a health-care institution. This strategy may affect consistent utilization of health-care institutions since some of them may abandon utilization of health care when they feel better and then use traditional healers and faith houses. Furthermore, we asked the participants their advice to other PLWHA. Their advice mostly was a reflection of what they practiced themselves:

*'Persons with HIV should pray to God for a miracle.'* (Female, 24 years, single, unemployed, participant 3, in-depth interview)

*'My advice is that people with HIV should have hope in God.'* (Female, 29 years, married, housewife, participant 7, in-depth interview)

*'HIV people have to trust in God and God can always change things.'* (Male, 48 years, married, company worker, participant 14, in-depth interview)

#### 4.5 Care choices

Some participants made care choices, which made them refrain from treatment or stop their treatment after they had started. Others chose not to tell their pastors but went for prayers alone. Many of the participants believed God could cure them of HIV and combined it with going to hospital for ART. It was also common for them to resort to religion early to solve problems, hence it was not unusual that visiting faith houses such as churches were the early choices participants made when managing their sickness:

*'I did not feel anything when I was told I had HIV because I know my God will heal me.'* (Female, 47 years, widow, petty trader, participant 17, in-depth interview)

### 5. Discussion

Our study focused on factors associated with PLWHA making care choices. Our participants are different from other PLWHA because they have tested themselves and sought care however they still gave insight in the stigma related processes which affect utilization of health care institutions. Few participants in our study experienced positive



support from their immediate family after disclosure of their positive HIV status and we found support for our main proposition that PLWHA still experience stigma in society including health care institutions, and in an effort to cope with stigma, utilized different care choices frequently which can affect utilization of health-care institutions. Our data revealed that poverty and religion were important in coping with HIV/AIDS as well as in making care choices, which affect utilization of health care institutions. Some PLWHA do not have money while others lost their jobs based on their positive HIV status, which has implications for them when deciding to seek care in health institutions especially since many people do not have health insurance or money to cover ART and care. The impact of stigma on PLWHA in Nigeria in the context of work constitutes an important barrier to seeking effective care and treatment. The right to work in Nigeria entails the rights of every person access to employment without any pre-condition except the necessary occupational qualifications (Iwuagwu et al., 2003). Moreover one of the guidelines in which Nigerian HIV/AIDS policy is based on is non-stigma and non-discrimination in recruitment, employment, admission and termination (National Agency for Control of AIDS (NACA), 2005) yet protection of PLWHA from dismissal from work poses some practical challenges. First, there is poor implementation of existing HIV/AIDS policies (National HIV/AIDS Policy Review Report, 2009) especially in private sectors that may cite other acceptable reasons (albeit non-HIV related reasons) for dismissal from work. Second, There is yet no legislation addressing HIV/AIDS related issues such as employment rights (Durojaye, 2003; National HIV/AIDS Policy Review Report, 2009) and the HIV/AIDS anti stigma bill is yet to be passed into law by the National Assembly of Nigeria. Oluduro and Ayankogbe (2003) noted that although there are treaties ratified by Nigerian government internationally including those concerning HIV/AIDS, some of them are yet to be domesticated (Oluduro & Ayankogbe, 2003). Furthermore treaties do not have force of law on their own and only treaties enacted into law by National Assembly of Nigeria can bind the Federal Republic of Nigeria (Oluduro & Ayankogbe, 2003). Despite these challenges, Nigerian citizens have the fundamental rights enshrined in the constitution that guarantees every citizen freedom from stigma and discrimination and therefore can be applied to PLWHA (Azinge, 2003) to protect PLWHA legally while expectation of the eventual passage of the HIV/AIDS anti stigma law by the National Assembly. A different study carried out in Russia also reported job losses by PLWHA (Amirkhanian et al., 2003) making securing of a living and finances an integral part of coping and care-seeking in health-care institutions. Conversely, those participants who were still working and financially capable were able to cope and had less need to ask people for financial help, and hence, successfully hid their status while utilizing health care facilities and taking ART.

Many of the participants went for HIV testing with a clear reason. This has implications for early HIV diagnosis and the use of ART, due to the subsequent delay in visiting health-care institutions. In addition, early voluntary counseling and testing (VCT) will prepare, give people knowledge and the self-efficacy needed to cope with and manage HIV/AIDS. This finding is consistent with a study carried out in Thailand, which showed that the majority of the men underwent HIV testing for health reasons, while the majority of women were tested following family events, such as a spouse's passing away or pregnancy (Le Coeur et al., 2009). Fear of being identified as someone infected by HIV increases the likelihood of people avoiding VCT (Nyblade et al., 2009).

Our data showed that the discovery and disclosure of a positive HIV status may lead to family disharmony, generating a lot of suspicions. The findings show that concealment and disclosure remained an uphill task for PLWHA. The concealment affects their self-efficacy in seeking care in health institutions, which in turn can lead to non-utilization of health-care institutions because they will not want to be seen there. This study showed that some of the participants who disclosed, experienced negative consequences while others received support. Some of our participants had problems when they went on the radio programme as part of the PLWHA association activities because they revealed their positive HIV status and people who knew them recognized their voices. This shows the downside of PLWHA becoming active in HIV programs and has implication for support from their partners which is necessary to be able to utilize health care institutions. Furthermore, non-disclosure contributes to the spread of HIV/AIDS when people have unprotected sex.

Society can sometimes condemn PLWHA giving birth to children (Lekas et al., 2006; Valencia-Garcia et al., 2008), which affects their reproductive rights and self-efficacy of seeking early care. Our data shows that both unmarried and married participants did not plan to disclose their positive HIV status to their spouses but did want to have children. This is significant in Nigeria because high value is placed on children (Isiugo-Abanihe, 1994). Non-disclosure of positive HIV status to their spouses has implications for not seeking early treatment, as well as for the prevention of vertical transmission. Criminal prosecution for HIV transmission has already been applied in a few cases in the United Kingdom, where research showed that the majority of PLWHA in the study were against criminalization of reckless HIV transmission, while a few felt it might be justified if it changed the behavior of PLWHA (Dodds & Keogh, 2006). While the protection of individuals in society is important, the sexual rights, disclosure problems and further stigmatization of PLWHA remain a concern. Brown and colleagues noted that there are existing legislative tools to respond to actions that constitute criminally harmful behavior arguing that HIV-specific laws to punish PLWHA is unnecessary, counterproductive and jeopardizes the human rights of PLWHA (Brown et al., 2009). Furthermore, direct or indirect inclusion of criminalization of vertical transmission pose serious consequences for female PLWHA as well as undermine the success of vertical transmission programmes so far achieved (Csete et al., 2009).

The participants' coping strategies were highly determined by the anticipation of negative reactions from society and the link to non-monogamous heterosexual transmission. They utilized different coping strategies to hide their condition since they believed it would not be accepted in society. The ability to cope with HIV/AIDS further depended on their marital status. Discordant partners found it more challenging to cope, because some were abandoned by their partners due only to the suspicion of being HIV infected. Our data also showed that married people received support better. The route through which participants felt they contracted their HIV virus was related to their emotional reaction and the support they received. Literature has pointed out that many women living with HIV/AIDS consider themselves as innocent victims in order to escape moral judgment from society (Doyal, 2009).

Furthermore, our study showed that gender played a role in the knowledge of partner's HIV status, as some of the female participants did not know their partners were HIV-positive and could not seek care when they were infected with HIV/AIDS. Schur (1984), noted that the overall subordination of women can lead to a snowballing effect because of the difficulty for them to achieve desired goals, such as getting tested for HIV. Women are

often dependent on their husbands for finances and decisionmaking in the family which are important when deciding to use the health-care institutions. Also, this has implications for prevention of vertical transmission for pregnant women with HIV/AIDS since they will not seek early treatment to initiate necessary ART. Studies have shown that husbands' refusal to disclose their status contributes to the spread of HIV infection (Neves & Gir, 2006; Chinkonde et al., 2009).

Our findings demonstrate the use and role of combined care choices in the care-seeking behavior of PLWHA such as visiting faith houses with taking ART from health care institutions. A combined care choice encourages opportunistic infections, ART drug resistance and complications that may result due to lack of drug adherence. This combination of treatments was also observed in health-seeking behavior for sexual concerns in Zimbabwe (Pearson & Makadzange, 2008), as well as in another study involving PLWHA in Ribeirao Preto, Brazil (Neves & Gir, 2006) corroborating findings obtained elsewhere.

## 6. Limitations

Although the findings from this study are informative, they must be interpreted in the context of some methodological limitations. First, this is a small exploratory, qualitative study. Second, the findings were organized within the explanatory model which was based on literature review of HIV-related stigma in Sub-Saharan Africa and so it is subject to the limitation of the search criteria used. Third, the findings cannot be generalized to the larger population. Fourth, the study was conducted with people who were open about their positive HIV status and belonged to a patient association. Finally, some of the participants were also on ART and enjoyed government, as well as social and company support.

## 7. Conclusion

In summary, the explanatory model applied in this study provided a framework for organizing the findings of this study. The model adapted from the Precede portion of the (Green & Kreuter, 1999) Precede-Proceed model was helpful in understanding HIV-stigma related problems, coping mechanisms and care-seeking behaviors of PLWHA which can affect utilization of health-care institutions (Mbonu et al., 2009). This study shows that certain determining and moderating variables are important for PLWHA, in order for them to cope with HIV/AIDS and to make care choices. These variables which are depicted in the model should be the target of context-specific interventions. The findings from this study can translate into practical issues if we understand how and why PLWHA seek care from health-care institutions. Societal reactions, whether anticipated or real, continue to play a vital role in the way PLWHA cope and seek care from health care institutions. It also makes people not to disclose their HIV status especially to their significant others such as their partners. This is because PLWHA believed that society blames them and perceives that it is only contracted through sex. Many PLWHA keep their HIV status information quiet but live with that burden to avoid societal judgment. PLWHA try also to compare HIV/AIDS in the way of route of transmission, lifetime medication and prognosis to other chronic illnesses as ways of coping even though they know in reality, HIV/AIDS is different medically and in terms of societal impressions, beliefs and reactions. Altering these coping methods, societal impressions and beliefs about HIV/AIDS is necessary in order for PLWHA to seek appropriate care. It is important that HIV patients are supported so that they are able to go

for HIV test and get effective treatment. Proper counseling goes a long way to help PLWHA to accept their status and prepares them to live with HIV. Clearly, PLWHA need psychological, medical and material support. Access to antiretroviral drugs remains a very important step in the care of HIV patients because when people have access to drugs, their health greatly improves and they are less prone to complications so they can go to work, have normal relationships and interact fully with the people around them.

## 8. Recommendations

The government should, as suggested by some of the participants, support PLWHA whose positive HIV status is exposed through creating a protective work policy and providing them with free ART, as this will be a motivator for other people with positive HIV status to come forward for help. The government should help in providing micro credits for those trying to set-up a living and doing business. This is important for PLWHA who are poor and jobless to enable them pay their user fees, buy regular drugs, do laboratory investigations and take care of their families.

Government should continue with efforts to educate the population on HIV/AIDS-related stigma which, when reduced, will enable people to go for VCT and seek appropriate care in health-care institutions in an early stage. Furthermore, education of people about the options of ART and possibilities of care will increase the self-efficacy of PLWHA.

Government should continue to involve and commit stakeholders such as media, religious and community leaders in educating people about HIV/AIDS, stigma and HIV/AIDS care as that will help people in making appropriate care choices. Policymakers should also involve PLWHA at all levels of consultation to ensure that all their needs are well represented. Special attention should go to youths through special targeted HIV/AIDS programmes. In addition, effective gender-specific policies that protect women but include the role of men should be integrated into programmes to ensure full utilization and support such as protection of women who find out their positive HIV status in antenatal care. Finally, the national HIV strategies should involve and support the members of vulnerable groups such as the association networks of PLWHA which are important to continue efforts of reducing the broader stigma in society and health care institutions.

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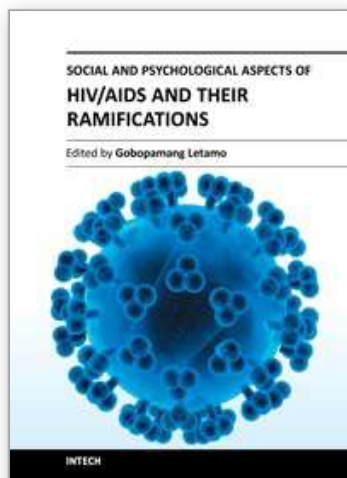
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This book has assembled an array of chapters on the social and psychosocial aspects of HIV/AIDS and their impact on HIV/AIDS and related behaviours. The book addresses key areas of HIV and AIDS, including, but not in any way limited to, care-seeking behaviour, adherence, access, psychosocial needs and support services, discrimination and the impact the epidemic has on various sectors of the economy. The book has seventeen chapters; seven chapters deal with social aspects of HIV/AIDS, four with psychosocial aspects of HIV/AIDS, and the remaining six chapters with the impact of social and psychosocial factors on HIV/AIDS and related behaviours. The book is an essential reading for academics, students and other people interested in the field of HIV and AIDS.

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