TO DISCLOSE OR NOT TO DISCLOSE:

ADULTS LIVING WITH HIV/AIDS IN BENIN CITY, NIGERIA

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PREFACE

This policy research paper is part of the on-going research of the *Centre for Population and Environmental Development (CPED)* on the research theme titled *"Health including HIV/AIDS and Development in Nigeria."* in the current strategic plan (2010-2014) of the Centre. People Living with HIV/AIDS (PLWHA) face the dilemma to disclose or not to disclose due to perceived stigma, discrimination and fear that may arise. Some faced self-inflicted fears, while reasons for non-disclosure to children include not matured, serves no purpose, children's shock and rejection, to prevent linking infection to past sexual behaviour and fear of stigma and discrimination. For those that disclosed their HIV status, experiences ranged from isolation, neglect, while others experienced acceptance, accommodation and integration from family members and close friends. This paper examines the pattern of self-disclosure of persons living with HIV/AIDS receiving treatment in University of Benin Teaching Hospital, Benin City, Edo State Nigeria. The paper also explores the explanation given by PLWHA on their decision to disclose or not to disclose their sero-status to family members.

We are particularly grateful to the *Think Tank Initiative* for the support to CPED which has enabled the Centre to carry out the study that led to this policy paper.

INTRODUCTION

HIV prevalence rate in Nigeria is 5.0% in 2003, while state-wide HIV prevalence ranges from as high as 10% in Benue, 8% in Akwa Ibom, 4.6% in Edo state, to under 2% in Ekiti, Oyo and Jigawa states (Federal Ministry of Health, 2006). It is estimated that with 2.9 million people living with the HIV virus, Nigeria has the second highest population of persons living with HIV/AIDS in 2007, after India and South Africa (UNAIDS, 2008). Yet, HIV/AIDS stigma remains prevalent in Nigeria and remains an important factor in the decision to be tested for HIV virus.

Studies in sub-Saharan Africa have documented the everyday abuse, discrimination and violence that PLWHA face (Moore et al., 2008; Herek & Glunt, 1998; Alonzo & Reynolds, 1995; Gilmore & Somerville, 1994). The serious social and health consequences to disclose or not to disclose one's HIV status to family members, including spouse, children and siblings and friends are well documented (Nostlinger et al., 2004; Kirshenbaum & Nevid, 2002; Lee & Rotheram-Borus, 2002; Schrimshaw & Siegl, 2002; Shaffer and Forehand, 2001; Armistead et al., 1999; Miller & Muyrray, 1999; Holt et al., 1998; Malcolm et al., 1998; Serovich et al, 1998; Rotheram-Borus, et al., 1997; Kimberly, et al., 1995; Simoni et al., 1995; Hays et al., 1993). Despite the enormous funds and time spent on HIV prevention in sub-Saharan Africa, barriers such as fear, discrimination and stigmatization continue to plague PLWHA willingness to disclose their serostatus (Schrimshaw & Siegel, 2003). However, there is growing comfort and willingness to disclose serostatus to health service provides (Greeff et al., 2008). Earlier documentation shows experiences of stigma, stereotype and isolation among persons living with HIV/AIDS in India (Bharat et al., 2001) and other African societies such as Botswana (Nyblade & Field-Nger, 2001), Kenya (Miller & Rubin, 2007), Zambia (Bond et al., 2002; Nyblade & Field-Nger, 2001; Yamba, 1997), Togo (Moore et al., 2008; Moore & Williamson, 2003), South Africa (Abdool et al., 2008; SImbayi et al., 2007; Varga et al., 2006) and Uganda (King et al., 2008; Mukasa et al., 2001). Hence, the fear of social isolation and rejection from families and other social systems continue to influence the decision to disclose or not to disclose.

Evidence also abound that parents face the heavy burden to share their HIV status with children, due to fear of confidentiality, stereotyping and stigma

(Emlet, 2008; Moore et al., 2008; Okuno, 2006; Arnold et al., 2005; Letteney & LaPorte, 2004; Dematteo et al., 2002; Le et al., 2002; Simoni et al., 2000, 1995). In places where disclosure is made to children, it is often to more matured children who are likely to respect the rights and privacy of their parent, as well as being emotionally developed to handle the disclosure (Moore et al., 2008). The emotional impact of HIV/AIDS is more severe in the contexts in which metaphors about HIV/AIDS ranges from being a death warrant to punishment for past sins committed (Omorodion et al., 2010). The difficulty with disclosure also hinges on the fact that the primary mode of contracting the disease in Nigeria is through heterosexual sex (UNAIDS 2010, 2008; Simon, 2006). Consequently, disclosure is likely to result in their children questioning their sexuality and asking questions they are not comfortable in answering. The tension in families is further worsened when only one spouse, particularly the woman is HIV positive (Shaffer and Forehand, 2001; Serovich et al, 1998; Rotheram-Borus, et al., 1997; Simoni et al., 1995).

In conclusion, disclosure of one's HIV status results in mixed outcomes. Available evidence shows that in a highly stigmatized context, disclosure of HIV status results is likely to result in negative outcomes, as one may experience ridicule, be segregated in public events, quarantined, or gossiped thereafter (Schrimshaw & Siegel, 2002; Lee & Rotheram-Borus, 2002; Moore et al., 2008). These reactions have been documented to further isolate the disclosers and prevent them from accessing and receiving the needed treatment, care and support in dealing with the disease (Moore et al., 2008). In other contexts, disclosure is known to lead to increased social support and reduced health problems such as depression and other psychiatric problems, while strengthening the ability to cope with the situation (Kirshenbaum & Nevid, 2002; Paxton, 2002; Klein et al., 2000; Holt et al., 1998; Hays et al., 1992).

In this paper, we examine the pattern of self-disclosure of persons living with HIV/AIDS receiving treatment in University of Benin Teaching Hospital, Benin City, Edo State Nigeria. We also explore the explanation why PLWHA choose to disclose or not to disclose their sero-status to family members.

METHODOLOGY

Research Setting

Edo state is one of the 36 states that make up the Federal Republic of Nigeria. It is located in the south-south region, and is one of the eight states that make up the Niger Delta Region of Nigeria. It has an estimated population of 3.5 million. The population of persons living with HIV/AIDS remains a guess work because many Nigerians including residents of Edo State are yet to be tested. The reasons for non-testing may range from the lack of testing facilities particularly in rural communities to the fear people have in knowing their HIV status. However, national figure show that the country has the second largest population of PLWHA, despite its HIV prevalence rate of 5% (UNAIDS, 2010, 2008).

University of Benin Teaching Hospital is one of the tertiary health institutions in Nigeria and the oldest federal funded health institution in Edo State. With this status, it hosts CEPHAR, the primary center for the administration of antiretroviral drugs in the state. It captures mainly PLWHA resident in the three Edo senatorial districts, namely, Edo Central, Edo North an Edo South senatorial districts. Clients attending the centre have increased over the past five years due to referral from private and other public health centers, as well as, the availability and accessibility to free medications, care and support being delivered.

Selection of Participants

Centre for population, environment and development (CPED), obtained ethical approval to conduct the study from the University of Benin Teaching Hospital Ethics review board. Following, the Centre gave a letter of introduction including the study contents and sample of interview guide to the head of CEPHAR, the department where PLWHA obtain care, treatment and support. The head of the department then linked the interviewer with the staff (counselors) in the department.

On the visiting days, a staff at centre informed the clients of the nature of the study. Then, they were asked to volunteer. Participants who verbally consented were recruited and the dates and time for individual interviews were scheduled to match the dates they came for visits at the center. Our commitment to anonymity and confidentiality was stated to all staff and participants. Members of staff were not present at the time of interviews. This approach was to give the participants the freedom to communicate with the interviewer.

Data Collection Procedures

Interview data were collected from the month of September to November 2010 on the experiences and challenges confronting PLWHA. The topics covered included personal HIV stories and experiences, experiences of disclosure, fear, stigma and discrimination. We also gathered data on personal characteristics. Interviewer obtained verbal consent from all participants. A total of 20 PLWHA attending CEPHAR, University of Benin Teaching Hospital, Benin City participated in the study. Participants in the study were adults, who had been diagnosed with HIV/AIDS and were clients of the center, visiting at least every three months for treatment, care and support.

One trained interviewer with training and experiences on conducting interview on sensitive issues such as HIV/AIDS conducted all the 20 interviews to ensure reliability and consistency in the interviewing process, including the ability to probe in depth. We also obtained permission to tape record the discussions, only five declined to be tape recorded. Interviews were held at a private space at the centre with those that volunteered to participate. The focus was to obtain from these participants how they navigated the process of disclosure, reasons for disclosure or for not disclosing, and who they chose to disclose their serostatus to. Those with HIV positive children were asked of their children's awareness and knowledge of their status and who provided care to these children when parents are at work. Interviews conducted in English and pidgin English were also audio-taped where permission is given otherwise, notes were taken during the interviews.

We adopted an aspect of grounded theory that entails the simultaneous process of data collection, analyses and description (Glaser, 1992; Glaser & Strauss, 1967). This meant a simultaneous analysis of data with data collection for the themes and patterns, which allowed us to identify most important categories, as well as emerging theoretical implications. N6 software was used for coding and analysis of interview transcripts. Validity and reliability of data were confirmed through regular consultations and discussions of emerging themes in order to have a common understanding.

RESULTS

Background Information on Participants

Sixty percent of the participants were women while forty percent were men. A majority, 50 per cent were single, 30 per cent were married and the rest 20 per cent were separated or divorced. Of this population, seventeen of them had children with their spouse or out of marriage. They were all adults and between the age of 20 and 40 years, with the mean age of 31.9 years. Participants were from diverse ethnic origins, with a majority from Benin (25%), followed by Esan (15%), and 10% each from Ibo and Yoruba, and only 5% from Ijaw-speaking group. A majority (85%) knew their sero status when they were asked to go for testing due to persistent illness such as cough, with the exception of one person who was detected at birth and two persons during routine ante natal care. They have been coming to the centre for over seven years, when free ARVs are being administered at the centre. The average age of their children was 18 years of age, with the youngest child of 10 years. Of the participants with children, only five stated that had a child with HIV/AIDS. Length of time since diagnoses ranged from 3months to 10 years.

Who do PLWHA Disclose their sero-status?

The findings show that initial disclosure was mainly to a family member including adult children. Disclosure was never made to underaged children. Secondary disclosure was to spouse or sexual partner, and in one case it was accidental, through testing in a private hospital. All participants had disclosed their serostatus to medical staff at the hospitals visited to date. The medical staff included doctors, nurses, counselors, laboratory technicians and pharmacy staff. However, on the question on disclosure, a majority of the respondents (40%) had disclosed their status to their parents only, 20% to both parents and siblings, 10% to children only, and 10% to both members of their nuclear families and friends. Of those who disclosed to friends, one was by coincidence because she asked and took the friend to the hospital for testing. Thereafter, the participant began to avoid the friend by moving to a new location and changing place of worship. Many participants with children did not disclose their status, neither did they disclose the serostatus of a child to their sibling. A few of the participants (25%) disclosed to a clergy.

Initial Reaction to Knowledge of Serostatus

In most of the participants, testing for their HIV status was requested by a physician based on their presentation to the clinic. Some came to the clinic as referrals from other hospitals mainly private. In very few cases did friends and family members recommend and took the participant to the hospital and demanded they get tested for HIV. In one case, the participant, a young boy simply went for voluntary testing when he saw free testing going on near his neighborhood.

Irrespective of how they got to the hospital and got tested, the initial reactions to the news about their HIV status were generally one of shock and disbelief.

A male participant, whose wife died two years before his diagnosis and never knew whether she was HIV positive noted:

> I was really shocked when they told me. I thought it was all over.
> But the doctor encouraged me.
> The doctor said it was not over then he referred me to UBTH, where I now get treatment and care.

A separated female participant said:

> I thought I was going to die so told everyone in my family but something funny happened when I told me daughter. She never came back to the hospital.

Initially, the above participant reported that "I kept it [the information about his serostatus] to myself at first. I have not told any other person apart from the doctor and my elder brother [who advised him to go to UBTH".

A male single participant noted:

> It can be emotional because of thinking.
> Sometimes we think and sometimes we forget that nobody knows and you begin to watch yourself and may as a young boy now I will not like to talk to some girls because
> I know what I have.

Reasons for non-disclosure to Children

Not Matured

Most of the participants reported that their children were too young and not matured enough to understand and handle the disclosure of their serostatus. The parent-child relationship often does not include communication on sex and sexuality matters. Therefore, communicating their serostatus meant opening up discussions on sex and sexuality. A mother of four children and with the last child, who is HIV positive stated:

> My children are still too young to understand such news, needless to understand the whole talk about HIV/AIDS.

One participant, whose child is HIV positive, noted that she has not informed her son of his status because:

> No, no, no, oh. He is just 10 years.

Although the parents (both HIV positive) bring him to the hospital for treatment and care, this child has a nagging cough and simply told to take his medicine so that the cough will go. The mother noted that what she tells the child is "do you want to cough again," and the child would "quickly go to take his medicine "often administered by older siblings. The siblings are told that if their brother "misses the medicine he will start to cough again and nobody wants him to cough like that again."

Another female participant who has older children noted:

> I do not leave with my children. I am divorced and the children blame me.
>
> Such information would further confirm the accusations of their father, involving infidelity.

The following extract from a father whose wife died and children (two daughters) were in post secondary school illustrates his reason:

> At the time of my diagnosis, my children were too young to understand.
>
> But, I am planning to tell the senior one, now that she is, she is grown up. You know, now that she is grown up I will call her maybe when she is on holiday and inform her of this thing. That is the senior one not the junior one.

Avoid linking Illness to past sexual behavior

A married female participant knew of her serostatus before marriage but failed to inform her husband. Rather she visited the hospital secretly to collect her medications under false reasons. However, after her marriage, she experienced a number of miscarriages and in one occasion, the doctor chose to conduct a series of test including HIV. Then they found she was positive but the husband was negative. Husband and wife were counseled separately and the wife (who knew she had HIV before marriage) accepted that the doctor disclose her serostatus to her husband but he should not divulge the fact that she knew she had it in the past. The woman said:

> Her failure to disclose was due to fear and the fact that her husband may link it to her past sexual behavior. She was afraid to lose him too.

Avoid distressing the children

In Nigeria, HIV/AIDS is known to be linked to death and such news sends panic to family members who will not want to lose a parent. Hence, participants had concern that disclosure will stress the children. Due to this concern, some parents chose not to disclose their serostatus to their children. A female participant said:

> I don't want them to feel bad and begin to think
> Another female participant noted that children would be worried that their mother is going to die and this is detrimental to the health of such children.

Another female participant mother of three said:

> I do not want my children to worry. They are too young. I will tell them later.

A married female participant with older children added:

> I did not tell my children because I fear losing them.
> They will be worried, confused, disappointed and traumatized.

Others reported that they did not want their children to bear the burden of keeping it secret, and feared they would one day disclose such information to other people. The following excerpts illustrate the point:

> Disclosing my HIV status to my children would make them to worry and become uncomfortable. They would fear if their friends know. I do not know how they would handle the news. You do not know who they will tell.

Another participant said:

> I have not told them because they will be scared to lose the only parent they have know.
> They will be worried and disappointed.

Disclosure to children serves No Purpose

A participant, who knew of his status as a child confirms that a child's knowledge of his status or that of his parent serves no purpose. The child may be too young to comprehend and therefore, disclosure serves no purpose. You may disclose and children simply do not understand the disease, but strongly believe it is deadly.

A mother of three, whose husband is also HIV positive noted:

> No. when you see me at work today, in my place they often refer to me as a man.
> I carry heavy load. I push wheelbarrow with my farm produce.
> At times I carry heavy load on my head as well. You will not believe it me.

Many do not feel the needed to inform their children because they are still strong to work and are not bed ridden. In addition, when they purchased medications at high cost (Such as 15,000 Naira, about $100 USD), and the stigma was too pronounced and there was silence over HIV/AIDS, disclosure was minimal or non-existent. With medications at no cost, there is no obligation to disclose.

Children's Shock and Rejection

There are children that react differently when told that one of their parents is HIV positive. For example, one of the participants who disclosed her serostatus to her daughter while in hospital stated:

> When my daughter came to the hospital, I told her what the doctors said, that was the last I saw her. She never came to the hospital again. I kept asking for her but she never came. When I eventually got better and can back home I called her and told her that it was a mistake that I thought that was what the doctors mean but I was all a mistake. She can see that I am well and back from the hospital. She hugged me and she was so afraid that was why she didn't come to the hospital again. She asked me to forgive her. I had to deceive my own daughter to win back my relationship with her

Many participants reported that they struggle daily not to reveal their status because they were shocked and afraid that death was eminent. A male participant purposely avoided telling his girlfriend because:

> I love her so much and sometimes I really want to tell her.
> But I am scared of how she may react.
> I don't know. I don't want to lose her

Stigmatization of PLWHA

Despite the various HIV/AIDS awareness and knowledge campaign in Nigeria, using the media such as radio, television and newspapers, many individuals and groups continue to stigmatize against PLWHA. A female participant noted that some despise and would not have anything to do with someone who is HIV positive. Due to such stigmatization, she would not disclose her HIV status to anyone. Thought she had disclosed it to family members, she now felt it was not the right thing to do. She reported her experience with her younger sister and brother's girlfriend who lived in the same house with her.

She reported that her younger sister always threatened to expose her HIV status any time they had a misunderstanding. Her younger sister would say:

> I will tell everybody that you are HIV positive

On the day she failed to plead with her sister not to expose her HIV status, she noted:

> She ran outside and started to shout calling the attention of all the neighbours,
> Come and see somebody who is HIV positive, come everyone have you ever
> Seen any HIV person? My sister is one, she is HIV positive.

A male participant, who reported he was infected from birth, reported his experience of discrimination from an aunt. He said:

> I have an aunt who is aware and at times, she wants me to know. She treats me somehow.
> I really wished she didn't know. I really don't like how she treats me.

He added that this aunt embarrasses him before other people He noted:

> She may just call me to ask me before other people if I have taken my medications.

A divorced female participant reported what her brother's girlfriend said:

> Aunty, I cannot drink water in the house where there is somebody with HIV not to talk about eating food. God forbid.

This participant noted that "I was shocked inside of me but I didn't show it and I also laughed because we live together and she has been eating and drinking in the same house where an HIV person lives. So I laughed out and she asked 'aunty why are you laughing or don't you feel the same way too". Rather than raise her awareness about HIV/AIDS by sharing some information with her, her reaction to the brother's girlfriend was:

> I too will not drink water from the house where I know someone who has HIV.
> She declined to enlighten this individual because according to her, she will not understand, rather she would conclude that was the reason she supports people living with HIV.

A female participant also reported her friend's stigmatization of persons she suspects to be HIV positive. She said:

> I have a friend who we do business together. Whenever we see a slim person or a sick looking person, she will say I think that person has HIV.

Another participant reported;

> She was very sick, so sick I did not even know I will be alive today so I told all my family members. Even my brothers

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> abroad----- I thought I was going to die.
> My whole body was filled with rashes. I could hardly talk. I did not know I will survive.

A married female participant, who believed strongly she got infected from a blood transfusion in a private hospital noted:

> They did the test and they said I have HIV.
> At once my mind went straight to the blood transfusion and I started to cry, I really cried because I could not think of anything else or anywhere else

A young male participant reported:

> I was very sad but after sometime I decided to cheer up.
> It is not the end of the world.

Another young male university graduate participant said:

> I was very sad, but what can I do. I decided to cheer up.

A divorced female participant with children described her initial reaction thus:

> I was weak. I felt sad very well. But what can I do. It has happened. I had a deep thought and took it like that.

A single male participant who has been HIV positive from childhood said:

> I was a little boy. I did not understand it as much as I do now.

He made an analogy of his reaction then to those of the children in the clinic for treatment and care:

> You see these little children. They are not told what they have, you can see they are in school uniform, they just know that they come to the hospital like once in three months and take medicine every day, nobody told them they have HIV.

An unmarried female participant described her initial reaction thus:

> I was very sad. I cried and I took the result home to show to my parents but I took heart when my parents encouraged me.

A married female participant recently diagnosed with HIV infection said:

> I was sad. But now I am trying to take it. I am trying to feel good although it is hard.

Deception: Hiding Medicine Labels

Most of the participants found various ways to hide their serostatus from their partners. One common way was to remove the labels on their medications. A single male participant, who is in a relationship where the girl is unaware of his HIV status said:

> Even if I take my medications she may not know what it is all about.
>
> When I get my medication, I remove the packs and the labels and just take them like that Even if she came across the medications, she will not know what they are.

Some participant deliberately avoided other PLWHA, who reside close to them. A male participant noted:

> You see that woman that just entered, she is my neighbor.
> I don't want her to see me.

This participant was hiding from his neighbor because:

> She may get home and tell her husband or anybody and I don't want that.

CONCLUSION

The data shows that most of the participants disclosed their serostatus to health workers, including physicians, counselors because they were more likely to protect their identity because of the confidentiality and anonymity guiding their profession and practices. Available evidence abound that health personnel were by the ethical code of their profession bound to keep health information about PLWHA confidential. Hence, PLWHA felt health professionals can be trusted, because disclosure to other persons including family members may result in discrimination and stigmatization.

Our data bear credence to other studies (e.g. Moore & Williamson, 2003) which show that family members can discriminate against family members living with HIV/AIDS. Hence, PLWHA may not feel comfortable disclosing their status to family members. Another reason may be that PLWHA do not want their families to be discriminated against in the community simply because of their own serostatus. Although disclosure to family members may reduce the burden of coping with the infection, PLWHA, including those in our study tended to keep their lips sealed rather than inform others. In cases where disclosure has been made, some have regrets because they feel they are discriminated against by such persons. There is therefore, more reliance on the health providers they interact with at least once every three months when they visit the centre for check up and to collect their medications.

The study shows that disclosure to at least one parent, particularly mother is prevalent and has been reported by previous studies. In this study, only one participant reported disclosing her status to her father whom she is very close to. This bears credence to existing studies that show low rate of disclosure to fathers (Armistead et al., 1999a, 1999b). This outcome is a consequence of the fact that children are closer to their mothers than their fathers primarily because of the authoritarian parenting (Omorodion, 2010), in which children are taught to obey and not question their fathers. Consequently, children grow up less comfortable in sharing intimate and personal information with fathers, while feeling more comfortable in discussing with their mothers Therefore, fathers are the last to be told intimate matters including one's serostatus. This finding is contrary to the findings in other societies, in which disclosure to others including parents and siblings is more prevalent than in the study. We also found that disclosure is often to those family members who are likely to provide care and social support, particularly the poor. Our data support the evidence that PLWHA disclosed their serostatus to those most likely to give them the care and support they need to cope with the infection.

Another finding is the low disclosure to spouses, particularly of wives to husbands (Miller and Murray, 1999; Nostinger, et al., 2004). This is understood in the light that the primary mode of HIV transmission in sub-Saharan Africa, including Nigeria is through heterosexual sexual intercourse. Therefore, it is deduced that a wife with HIV infection must have contracted the virus from extra marital relationship and infidelity. This bears credence to the findings from Brazil that gender and sexuality also play a role in the decision to disclose or not to disclose (Rasera et al., 2004).

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