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CHALLENGES AND EXPERIENCES OF PERSONS LIVING WITH HIV/AIDS IN BENIN CITY, EDO STATE, NIGERIA

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PREFACE

This policy research monograph is part of the on-going research of the *Centre for Population and Environmental Development (CPED)* on the theme titled "Health including HIV/AIDS and development in Nigeria". This study explores the challenges and experience of persons living with HIV/AIDS receiving treatment in University of Benin Teaching Hospital, Benin City, and Heart to Heart Clinic in General Hospital, Uromi, Edo State, Nigeria. In addition, the study examines the reasons for disclosure and non-disclosure to children, family members and friends. The findings indicate that 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. However, there were a number of cases (30%) where PLWHA concealed their status from spouse and sex partners, which further increases the susceptibility and vulnerability of such persons to HIV infection. The study concludes that fear, stigma and discrimination will continue to hinder disclosure of serostatus, unless there is more emphasis on integrating HIV seropositive individuals into the community and invariably reduce the extent of discrimination and stigma.

CHAPTER ONE

INTRODUCTION

As at 2007, Nigerian population stood at 148,093,000 with an annual population growth of 2.1 (UNAIDS, 2008) and the United Nation Development index ranked Nigeria 154th out of 179 on the human development index (UN, 2006). 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). In addition, HIV prevalence is higher among youth as it stood at 13.3% in 2000, with female accounting for approximately 74.6% (WHARC, 2003).It is estimated that with 2.9 million people living with the HIV virus, Nigeria has the third highest population of persons living with HIV/AIDS in 2007, after India and South Africa. This is likely to further reduce the life expectancy of the Nigerian population that stood at 48 years in 2007 (UNAIDS, 2008). Despite the fact that the funds spent by the Federal Government of Nigeria on HIV and AIDS from national sources stood at 10.8 million US dollars, stigma and discrimination against PLWHA remain common and is 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 & Murray, 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 providers (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; Lee et al., 2002; Simoni et al., 2000, 1995). In places where disclosure is made to children, it is often to the more matured children who are likely to respect the rights and privacy of their parents, 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 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 et al., 2001; Serovich et al, 1998; Rotheram-Borus, et al., 1997; Simoni et al., 1995).

It can therefore be stated that 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 lead to negative outcomes, as those concerned 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).

CHAPTER TWO

THEORETICAL FRAMEWORK

In this section, we highlight the ways in which the inter-locking concepts of fear, stigma, discrimination, empowerment and critical consciousness and other socioeconomic, cultural and demographic factors influence the decision to disclose or not to disclose stressful events or illnesses that would result in neglect and stereotyping. These inter-locking concepts provide a useful starting point for theorizing the processes whereby empowerment and critical consciousness (Rappaport, 1987) might serve as a mechanism for promoting the decision to disclose one's HIV serostatus and build health-enabling community (Tawil et al., 1995).

Stigma, Consequence and Social Influence Theories

A number of theories, such as Consequence (Emlet 2006, 2008) and Social Influence, and Generativity, or concern for others provide explanations for disclosure or non disclosure of one's HIV positive status. Fear of the stigma and discrimination that will follow disclosure of one's serostatus, inhibits individual's disclosure and access to voluntary counselling and testing, which conversely become barriers to treatment, care, support and prevention. For example, studies indicating high anticipated stigma and discrimination resulted in non disclosure (Abdool et al., 2008), while studies anticipating decreased stigma led to disclosure (Liu et al., 2006). Other studies (e.g. Emlet, 2008) reported that maintaining a culture of silence is a way of avoiding stigma.

Similarly, much of the studies based on the disclosure experiences of persons living with HIV/AIDS (PLWHA) show that physical, social, cultural, economic and demographic factors influence the decision to disclose or not to disclose. Such influence is further inhibited or facilitated by an individual membership in a collectivist or individualist group. The basic assumption is that membership in a collectivist group is likely to make the individual to assess and consider the reaction of the members of the group to disclosing one's serostatus. Therefore, if the reaction is seen to be negative in terms of the stigma and discrimination that may follow upon disclosure, the individual is likely not to disclose the HIV positive status. On the contrary, an individual whose membership is in an individualist group, and has been socialized to value individual success and consequence is more likely to disclose because disclosure is likely to bring him support and care and improve the quality of life.

The underlining assumption to these two tenets to disclosure is that an individual is a rational being, capable of making the right decisions that are suitable within a particular context. Unfortunately, man and woman are not that rational as their decision making can be fluid and irrational, thus putting them at risk of contracting HIV infection. For example, studies abound that although knowledge about HIV has improved immensely in the last decade, there is still enormous failure in translating this knowledge to HIV preventive behaviour (UNAIDS, 1999). Rather, more individuals, particularly in sub-Saharan Africa continue to engage in risky behaviour such as having multiple sex partners, low use or incorrect use of condom, and the continued existence of cultural practices such as widowhood rites that continue to expose the people to HIV infection.

The belief that humans are rational has informed HIV prevention activities that focuses on changing individual behaviour through HIV education without taking cognizance of the influence of the social-cultural factors including beliefs and practices, particularly in aspects of local livelihood needs such as money for survival and income providing skills such as traditional healers.

Some studies further link a person's identity development to the decision to disclose or not to disclose HIV positive status. These studies document the steps taken in the journey to disclosure or in adapting to living with HIV. For example, a study on a high representation of gay men has identified three steps in the process of disclosure, the diagnosis phase involving disclosure to significant others in one's life; immersion phase in which membership and involvement with the HIV community leading to the centrality of HIV in one's identity to public disclosure; and the integration phase, which is linked to situational disclosure, where HIV becomes an important part of one's identity. Thus, disclosure becomes discretional and well thoughtfully made, resulting in post-diagnosis social networks that provide support for its membership, such as those in Heart-to-Heart centres (Miller and Rubin, 2007; Serovich et al., 2005).

With Consequence theory, the individuals focus more on the consequences or reactions of others on their disclosure. Studies supporting this theory (Emlet, 2006, 2008) show that perceived positive consequence led to disclosure to family, friends and casual sex partners while negative consequence such stigma and discrimination, isolation or fear of abandonment and violence led to non disclosure. On the contrary, social influence theory posits that disclosure is inhibited or facilitated by the communities one associates or identifies with. For example, studies show (e.g. Stenger, 1996; Zea et al., 2007) membership in communities where HIV is better understood makes disclosure less stressful. Other factors reported to facilitate disclosure include as marital status, attendance in HIV services for more than two years and knowledge of partner's serostatus (King et al., 2008), desire to reduce transmission and to increase access to support services and to prevent vertical transmission (OHTN, 2008).

Another theory is Erickson's developmental phase of generativity, which posits that concern for the well being of others acts as a motivator to disclose one's serostatus (Greeff et al., 2008). Other studies (e.g. Emlet, 2008) the desire to break the culture of silence and seek support from others through prayers influence disclosure. However, while an individual may want to disclose, anxiety, fear of stigma and fearing the impact of disclosure on other family members may further inhibit disclosure. However, counselling, education, strength from faith and peer-support systems also make disclosure possible (OHTN, 2008). Some studies report that PLWHA are more likely to disclose to health care professionals (Greeff et al, 2008). There are several studies from developing countries which indicate that disclosing to health care professional was difficult for fear that they would disclose to others in the community, due to lack of professionalism and severe punishment in place for such health care providers. In addition, visiting HIV/AIDS treatment centres also create fear of identification as HIV positive person (Greeff et al., 2008)

Based on the above explanations, Peretti-Watel (2006) identified six typologies of disclosure: systematic disclosure, selective disclosure to fewer significant others, and uncontrolled disclosure colleagues. The systematic disclosure involves a high level of disclosure to adults with the exception of children often seen as not matured or may not be able to keep it secret from others and colleagues. The individuals in this category are more likely to report experiences of discrimination from relatives, friends and sexual partners. Individuals that make selective disclosure to fewer significant others have low levels of concern for disclosing to fathers, children, other relatives and colleagues and uncontrolled disclosure to friends. The uncontrolled disclosure to colleagues group adapts a mixed disclosure approach, which involves disclosure to friends, while concealing serostatus from children and family including siblings. The uncontrolled disclosure to relatives and individuals who are likely to disclose freely to family, particularly parents. These are persons who are more likely to abuse alcohol and have low educational attainment. There is the fifth group the concealment from fewer significant others group, comprising those that have no family or colleagues, and therefore are likely to conceal or hide their serostatus. These persons are older and are more likely to be migrants with lower education levels, more of women than men, and comprising an overrepresentation of men infected through having sex with men (MSM). The final group consists of the followings: migrants and newly diagnosed individuals who are noted to practice systematic and successful concealment of their serostatus from principal partners. Concealment and uncontrolled disclosure is associated with poor adherence to medications. Another study on MSM, identified five typologies based on the method of disclosure and not disclosure patterns, which focus on who disclosure is made. These five typologies are: point blank disclosure; stage-setting, whereby an individual provides clues leading up to a direct disclosure; indirect; buffering, or asking a third party to disclose; and seeking similar, or recreating community with others who are HIV positive.

Recent studies (e.g. Kalichman et al., 2005) are focusing on the link of knowledge and impact of self esteem development Intervention research is emerging that seeks to understand the impact knowledge and esteem development on comfort with disclosing. Other attempts (e.g. Kalichman, 2001) on understanding disclosure focus on developing assessment tools to understand personal efficacy in disclosing. This tenet argues that higher stigmatizing attitudes results in underutilization of HIV services and reluctance to disclose one’s diagnosis (Pulerwitz et al., 2008). Older adults with HIV are known to have the least support due to non-disclosure, as serostatus may be linked to past sexual experience. As such, they will experience lack of emotional, social and practical supports (Schrimshaw and Siegel, 2003). Some studies from Africa show that mass media increase the likelihood for disclosure and on risk reduction (Hutchinson et al., 2007; Abdool et al., 2008). Moreover, having a confidant in one’s life also facilitates disclosure to such person (Emlet, 2006).

Empowerment and critical consciousness

Critical to any discussion on empowerment are the issues of gender and power. Available evidence show that empowerment play a fundamental role shaping health-enhancing behaviour such as HIV prevention (Campbell, 2003, 2005; Rappaport, 1987). The basic assumption is that “powerlessness” or lack of control over your life situations/conditions is more likely to undermine the health of an individual or group of persons or a community (Wallerstein, 1992). Often, disempowered people are disadvantaged and marginalized, which is a testimony to their lack of human and material resources, as well as a consequence of their cultural norms, beliefs and values. While the provision of human and material resources can be facilitated externally through schooling and provision of capital through micro-credit, cultural factors that dis-empower females through the subordination of female to males, and the use of double-standard to perpetuate differential behaviours among boys and girls. Hence, Bandura (1986) argued that disempowered people irrespective of how they feel in terms of having control over their behaviour or self are less likely to engage in health-enhancing behaviour, which in this paper included HIV prevention practices. Advocates of Bandura (1986) posit that empowering an individual through the use of training programs to develop self assertiveness would promote the empowerment of the individual.

However, this approach to building empowerment is known to result in psychological empowerment. Critics have described such empowerment as superficial and inextricably linked to political and economic empowerment. For such critics, political and economic empowerment that gives the marginalized power and control over their bodies and means of production is obtainable through participatory and bottom up approach that gives the marginalized and disadvantaged group of people such as the rural population the capacity and freedom to improve their conditions using local resources that are cost effective and comprehensible to their understanding. This has been documented to bring real and not superficial changes that are easily erasable. Such real changes lead to success stories while its absence is likely to result in failure of programs and ability to imbibe safe sex practices (Trawil et al., 1995). In addition, it has been argued that empowerment by itself is insufficient to bring the desired results envisaged through empowerment.

We also need to promote critical consciousness, which according to Paulo Freire (1996) involves two components, development of intellectual understandings of the way in which social conditions have fostered peoples' situations of disadvantage. In this study, this involves some sort of intellectual understanding of the way in which gender and lack of power shape the decision to disclose or not to disclose one's HIV serostatus. Such intellectual understandings are paramount operating conditions for persons living with HIV/AIDS (PLWHA) to see the value of disclosing their serostatus despite their fear of stigmatization and discrimination. For example, disclose is likely to lead to support and care from family and friends and thereby promote healthy living such as quality sexual health through safe sex practices and not having multiple sex partners as well as adhere to proper treatment routine. From a Freirian perspective, such understandings would encourage PLWHA to support one another, evolve support group and facilitate family support in ways that will enhance their sexual health and keep them away from practices and behaviours that are less endangering of their sexual health.

Critical consciousness development goes through a number of stages. First stage known as "intrinsic thought", depicts a period in which the individual or persons are naïve and do not have the ability to engage in critical discourse. Accordingly, the people are ignorant of the ways in which their social context influence and undermine their well-being. The final stage is referred to as the 'critical transitivity', which is marked by the interaction between critical thought and critical action. This critical action is possible through the peoples' ability to have a more encompassing and critical perspective of their disadvantaged conditions. However, there are situations in which people fail to adapt a critical eye to their conditions but rather develop what is termed as adapted consciousness during which a person accommodates the conditions that hamper their critical discourse. Rather, the person adapts an authoritarian and a critical frame of mind

To Disclose or Not to Disclose

Available evidence abounds on the factors influencing the decision to disclose or not to disclose one's HIV serostatus. Studies have shown that experiences of disclosure are impacted upon by fear, stigma and discrimination. Yet, existing studies report that disclosure of stressful events has positive impact on the disclosers such as increased social support and care and reduced health problems (Deriega et al., 1993; Pennebaker et al., 1990).This notwithstanding disclosure remain difficult, because disclosers may be ridiculed, avoided or gossip particularly with HIV infection that remains surrounded by mystery in terms of the non consensus or agreement about its origin and has no cure. Studies from sub-Saharan Africa continue to note that PLWHA continue to experience isolation and lack of essential support (Deriega et al., 1993, Omorodion et al., 2010).

In sub-Saharan Africa, PLWHA and their families continue to be stigmatized, experience discrimination and abuses. Such experiences include being abandoned by loved ones, ostracized, disappear from their community or killed upon disclosure of their HIV positive status (Bujura, 2000; Moore and Williamson, 2003; Campbell et al., 2005; Muula, 2005). Accordingly, fear of stigma, discrimination within one's cultural settings influence the decision to disclose. Studies focusing on parents who are HIV positive show that parents worry and experience anxiety about sharing their serostatus with their children. The reasons for such worry include fear that children will not keep it secret or they may experience differential treatment from them (Rotheram-Borus et al., 1997; Dematteo et al., 2002). Such fear is known to result in mothers' "relatively low rate" of disclosure of their serostatus to children (Schrimshaw and Siegel, 2002). This trend occurs because of mothers' fear of children abandoning them, as a result of their negative stereotyping of PLWHA (Armistead et al. (1999a, b). There are however cases where mothers are willing to disclose their serostatus to mature children who are capable or mature to cope with such disclosure (Ostrom et al., 2006). Therefore, others tend to disclose their status to older children due to their emotional maturity (Armistead et al., 1997; Shaffer et al., 2001).

Disclosure is also hampered by the peoples' perception of HIV/AIDS as a killer disease that has no cure. For some, it is the punishment for sins. The situation in sub-Saharan Africa, particularly Edo State of Nigeria is further deplorable due to lack of resources for retroviral therapies and the fact that disclosure causes strain on all members of the family. Also pertinent is the assumption and belief that HIV infection is an outcome of one's conceptualization of sex and sexuality, topics that are rarely or never discussed between mothers and children; and the fact that transmission is primarily through heterosexual sexual intercourse (World Health Organization, 2003); and since sex and sexuality are not topics that parents discuss with their children (Oshi et al., 2005). Similarly, parents are more likely to feel parents may feel very uncomfortable disclosing their seropositive status to their children because of fear of children asking very personal questions that parents may be shameful to respond. They may fear that children may ask questions that would be difficult and shameful for them to answer. Hence, the argument that disclosure of HIV positive status may be stressful or threatening to human existence events or conditions considered threatening to one's life is complex (Kimberly et al., 1995; Serovich et al., 1998). Accordingly, disclosure of one's HIV positive status remains a challenge. However, disclosure may lead to obtaining the necessary resources for coping with the infection and for survival

A perusal of the literature also depicts disclosure to result in social support (Hays et al., 1992), which invariably impacts positively on the psychological and mental health of PLWHA functioning (Klein et al., 2000). For example, Holt et al. (1998) study reported that disclosure assisted British men in coping with their serostatus and enhanced the productivity of and well-being of PLWHA in Africa and Asia-Pacific region (Paxton, 2002). Notwithstanding, parents disclosure to children remains the most difficult (Tompkins et al., 1999). In addition, Armistead and Forehand (1995) and Murphy et al. (2001) noted that parents' disclosure of their HIV positive status reduces the state of confusion and anxiety in children when compared to children whose parents failed to disclose their serostatus. Disclosure allows children to ask questions and overcome fear and anxiety (Doll and Dillon, 1997). Furthermore, Brown and Powell-Cope (1993) noted that family relations are improved and based on trust and honesty, which lead to fulfilling life events.

This study attains two goals. First, it examines the journey and pathways leading to the decision to disclose or not to disclose their HIV serostatus among PLWHA seeking treatment in University Teaching Hospital, Benin City and Heart to Heart Clinic in General Hospital Uromi. Secondly, it explores the reasons why these PLWHA disclose or did not disclose their serostatus to their children and spouses.

CHAPTER THREE

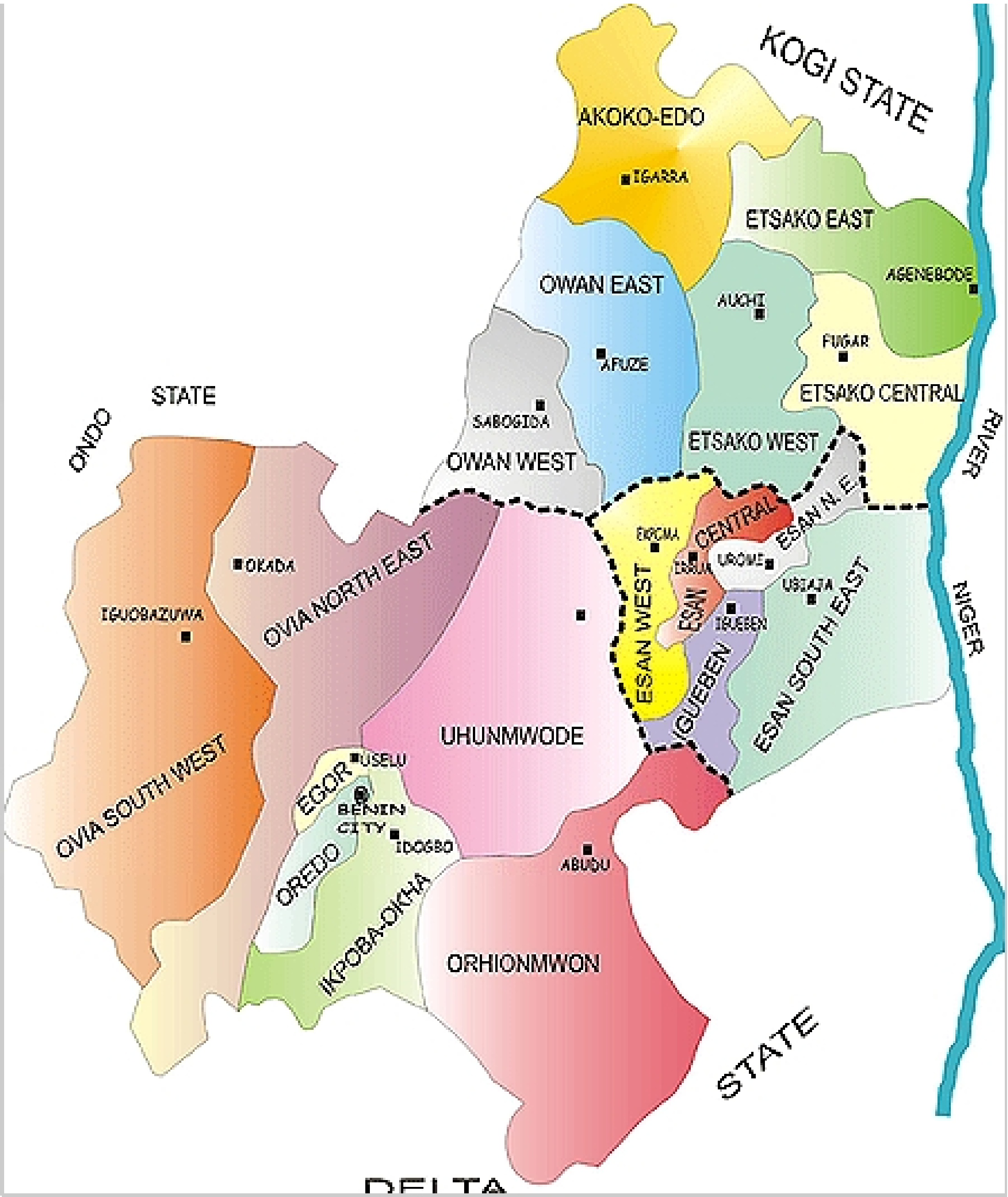
METHODS

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 eighteen local government areas, namely: Akoko Edo, Egor, Esan Central, Esan North East, Esan South East, Esan West, Etsako Central, Etsako East, Etsako West, Igueben, Ikpoba Okha, Oredo, Orhionmwon, Ovia North East, Ovia South West, Owan East, Owan West and Uhunmwonde. It has an estimated population of 3,233,366 million. Benin City, the headquarters of Edo state is popularly known as an ancient city and has a population of about 3.5million people. 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). The study was carried out in Benin City, the capital of Edo State and the headquarters of Oredo Local Government Area. University of Benin Teaching Hospital (UBTH), a tertiary health institution and the oldest federal funded health institution in Edo State was the study site. It is a 550-bed facility with over 20 health departments. It offers the public both secondary and tertiary health care. The hospital was established by the Federal Government of Nigeria in 2002. In 2007, the PEPFAR unit had an enrolment of 3,500 PLWHA. This unit is funded by the Federal Government of Nigeria and the United States President's Emergency Fund for AIDS relief. The unit offers voluntary counselling for HIV, confirmation of HIV positive cases and full pre-assessment investigations for confirmed cases before categorization into eligible and non-eligible individuals for the administration of antiretroviral drugs (ARV).

With this status, it hosts PEPFAR, the primary centre for the administration of subsidized 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 centres, as well as, the availability and accessibility to free medications, care and support being delivered. The ethical committee of the University of Benin Teaching Hospital, Benin City, Edo State and Nigeria gave approval for this study.



MAP OF EDO STATE

Heart to Heart Clinic

Heart to Heart Clinic in Nigeria was established in 1999 to join in the struggle against HIV/AIDS an epidemic ravaging sub-Saharan Africa in the past two decades. The emphasis is on prevention, care, education, support and research. It is a national project between Global Initiative for AID Nutritional Therapy (GIANT) and Endurance and Love Organization Inc. It is under the leadership of Dr. Alawode Oladele. The common goal of the program is to use their expertise and dedication to fight HIV/AIDS in Nigeria, by channelling their resources through American and European health providers, physicians and nurses. Their main effort focuses on the provision of food, drugs, books, toys, and equipment, and hold seminars on the prevention and education of HIV/AIDS in schools, hospitals and colleges. So doing, it contributes to the reduction and elimination of fear, stigma and discrimination facing PLWHA in their everyday living. This initiative is to improve their quality of life through building and nurturing an enabling quality environment that puts into their work culture-specific challenges that are detrimental to the well being of PLWHA. In the last five years, its focus has been on equipping hospitals and medical Centres in Nigeria. In addition it has been supporting the clothing and feeding of the deprived. It also provides PLWHA free healthcare.

Presently, General Hospital Uromi, located in Esan North East Local Government Area houses one of these Heart-t-Heart centres in Nigeria. It is the only centre where PLWHA can obtain free healthcare. Therefore, many PLWHA have to travel long distances from other four Esan LGAs to collect their medications. The long distance, cost of transportation and the absence of a permanent full time pharmacist are some of the challenges reported by the participants in this study. Despite these challenges, most participants noted that they look forward to their visit because it gives them opportunities to interact, socialize and share worries and anxieties with other members who have come together to form a support group. They are also able to ask question such as “how to have HIV free baby through natural conception and delivery.

Selection of Participants

This study was based on a convenient sample of 20 persons living with HIV/AIDS (PLWHA) receiving treatment from PEPFAR, at University of Benin Teaching Hospital (UBTH), Benin City participated in the study and ten women in HIV support group of Heart to Heart clinic located in General Hospital, Uromi.. The primary criteria for selection were that the participant had been diagnosed with HIV/AIDS, and were clients at the treatment, support and care centre of UBTH, Benin City and General Hospital, Uromi. Participants in the study were adult men and women (UBTH) and only women (Uromi), who had been diagnosed with HIV/AIDS and were clients of the centre, who visited at least every three months for treatment, care and support.

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

On the clinic days, which were the days the interviewer met and interviewed the participants, a staff would first inform the clients of the nature of the study. Then, they were asked to volunteer and told that participation was not mandatory. Our commitment to anonymity and confidentiality was stated to all staff and participants. Participants who volunteered to participate gave verbal consent and interview dates and time scheduled. The time of interview often matched their visiting days to the centre. Members of staff were not present at the time of interviews. The absence of the health providers was to give the participants the freedom to communicate with the interviewer.

We conducted interviews with adult volunteers from the HIV/AIDS support group on the days they visited to collect their medications. The focus with this group, mainly women was to provide a gender perspective to the experiences of PLWHA. The main thrust was to listen to women's stories of their journey to being diagnosed and how their personal experiences and challenges from that moment. An experienced moderator listened to the women's stories, which were either recorded with the consent of the participant or left the note taker to take rich notes from the narratives. A total of 10 women provided us with their personal stories. Due to the sensitive nature of the topic and the need to maintain consistency in the way questions were asked, only one interviewer conducted the interviews.

Data Collection Procedures

Interview data were collected from the month of September 2010 to February 2011 on the challenges and experiences facing PLWHA. The topics covered included personal HIV stories and experiences, experiences of disclosure, fear, stigma and discrimination; and their journey to being diagnosed with HIV infection. We also gathered data on personal characteristics. Interviewer obtained verbal consent from all participants. The experienced interviewer, who has worked on a larger project on HIV prevention at the Centre for Population, Environment and Development (CPED), funded by Global Health Initiative and International Development Research Centre (IDRC), Ottawa Canada conducted the interviews with UBTH participants and moderated the focus group discussion with the participants in the Heart to Heart Support group in General Hospital, Uromi. She also asked the participants to name all the people to whom they disclosed their serostatus. The discussions further investigated the reasons for disclosure and non-disclosure, particularly to children, other family members and friends.

The female trained interviewer with training and experiences on conducting interviews and moderating focus group sessions on sensitive issues such as HIV/AIDS conducted all the 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 transcribing the tape immediately after the interviews and subsequently analyzing the transcriptions. Data analysis involved the two authors reading and re-reading the transcriptions to identify the merging themes. The authors met and discussed regularly to examine and sort out their common codes and emerging themes. In accordance to LeCompte and Schensul (1999), validity and reliability of data were confirmed through regular consultations and discussions of emerging themes in order to have a common understanding.

CHAPTER FOUR

FINDINGS: PARTICIPANTS FROM UNIVERSITY OF BENIN TEACHING HOSPITAL, BENIN CITY

Background Information on Participants

The socio-demographic characteristics of the 35 PLWHA who participated in the study can be summarized as follows: Sixty percent of the participants were women and forty were men. A majority, 40 per cent were single, 28.6 per cent were married, 22.8 per cent were separated or divorced and 8.6% were widowed. Of their religion, (62.9%) were Christians, 22.9% were of traditional/indigenous faith and 14.2% were of Islamic faith. 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 (42.9%), followed by Esan (34.3%), and 14.3% of Etsako origin and Ibo 8.5%. A majority (85%) knew their serostatus 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 serostatus?

The data show that initial disclosure was mainly to a family member including adult children. Disclosure was never made to under-aged 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, counsellors, 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, friends and family members recommended and took the participant to the hospital demanding to be 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 neighbourhood.

Table 1: Background Characteristics of Participants

Characteristics	**Number**	**%**
Gender		
Female	21	60
Male	14	40
Marital Status		
Single	14	40
Married	10	28.6
Separated/Divorced	7	20
Widowed	4	11.4
Religion		
Christian	22	62.9
Muslim	5	14.2
Traditional	8	22.9
Others		
Ethnic Group		
Benin	15	42.9
Esan	12	34.3
Etsako	5	14.3
Ibo	3	8.5
No. of Children		
Female	10	55.6
Male	8	44.4
Disclosed HIV status to children		
Females		
Yes	18	51.4

No	7	20
Males		
Yes	7	20
No	3	8.6
Mean Age of Participants	31.5	
Mean Age of Children	**18**	
Mean Number of Children Ever Born	**5.5**	
Average Length of time since diagnosis	**4**	

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 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 behaviour

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 counselled 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 behaviour. 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 keep 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 known.
> 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 their 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. I laughed out and she asked: 'aunty why are you laughing or don't you feel the same why 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 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 well, well. But what can I do. It has happened. I think far, far.

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 neighbour.
> I don't want her to see me.

This participant was hiding from his neighbour because:

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

CHAPTER FIVE

FINDINGS FROM WOMEN'S STORIES OF EXPERIENCES WITH HIV/AIDS INFECTION

Processes leading to Diagnosis and Disclosure of HIV Status

The thirty women interviewed were diagnosed through HIV voluntary, counselling and testing routine. But, the journey to becoming tested was described as the most painful and resource depleting experience in their lives. The journey of all the women but two, started with their spouse having prolonged illness that took them from home-based care to traditional healer and to the hospital. Often, spouses failed to disclose to their partners the nature of their illness once they had knowledge of their HIV serostatus. In these cases, the women did not experience any symptoms of the disease until after the death of the man.

A woman said:

> At every stage of my husband ill-health, my family members held responsible for his illness. Yet, they claimed they had no knowledge of the disease. Even after they knew he was HIV positive, they kept it away from me.

Another woman noted:

> My husband and I lived in Abuja. He became seriously ill from one symptom to another and doctors could not tell us what caused his illness. At one point he ran an HIV test and was asked to come the next day. On this faithful day, he chose to visit the hospital alone, while I stayed at home. On his return, he packed his belongings and travelled back to place of origin, Uromi. He became very ill. On one fateful day, he walked of the parents' residence never to be seen up to this very day. My in-laws sent for me saying my mother-in-law was seriously ill. On my arrival, I was told of what happened to my husband. Thereafter, I took ill, came down with rashes and became very slim. My sister recommended I visit the Central Hospital in Uromi, where I was diagnosed HIV positive and counselled. I went back home, got my in-laws together and my parents and broke the news. It was received with shock but it gave an explanation to a probable reason for my husband's ill health and subsequent disappearance.

There was a pathetic case in which:

> The woman experienced itching on her back for a prolonged period before a boil developed. The boil got bigger and bigger to the point she could barely walk straight. Her family took her from one

> traditional healer to another with no relief. On one day, her brother took a razor and opened up the boil and the substance that came out was so much and with very strong and bad odour. This left a very deep hole on my back that I could bare walk. At this junction, a family member demanded I be taken to the Central Hospital in Uromi. On reaching the hospital, the doctors and nurses continued to treat my wound. However, I was losing weight so fast and the doctor asked for a number of tests and I was found to have that disease, HIV. I thought was eminent and got very, very low. Then I was counselled that there are medications that one takes and will leave a normal life. I was also counselled on the importance of engaging in protective sex. This was three years ago and today, I have gained weight, look healthy, go about my normal activities, and unless I disclose my status, no one can ever guess I have such disease.

One of the women reported:

> I had a very sick husband that she took from hospital to hospital until they got to UBTH. At UBTH he refused to be tested for HIV and was taken back home by his sisters. My husband and I continued to have sex. When I came back to Uromi, I started demanding to be tested, when I got ill with fever. But the three doctors I met declined to get me tested. I then got pregnant, and at the ante natal clinic, we were given information on HIV/AIDS as part of the routine and were tested. When the test results came, I was called aside, counselled and informed of my status. Then I worried over my unborn child. I was put on drugs and counselled either not to breast feed or to breastfeed only for three months without water and wean the baby at three months. It was after delivery, I disclosed to my mother because I needed her support in following the post delivery routine. She moved in with us and helped me in weaning my baby after three months. Baby was tested after one year and three months and was HIV negative. My husband finally got tested and was HIV positive. I blamed him, because he had multiple sex partners. Now, he is sober but is too late. He still shies away from coming to the hospital for his drugs. I now collect them for both of us and we take our medications together. I am here at the hospital today to get information on what I can do to get another HIV negative baby. I desire to have another child.

A woman reported:

> My husband was very sick and we spent all our money in seeking cure from one treatment home to another until he died nine years ago. Thereafter, I got seriously ill three years ago. My children and close family members, my sisters took me to the Central hospital where I was tested HIV positive. I called my children, who were grown up and informed them. They supported and stood by until I recovered. Being on my drug routine, I got ill and have remained strong.

Another woman experienced wasting and got very slim. She reported:

> After her protracted illness, her husband sent her away. Thereafter, she was tested and found to be HIV positive. She was give drugs, told its importance and followed kept to the drug routine. Ever since, I have been looking healthy and no one can tell I have that disease, unless I disclose my status.

There was another one woman in this support group of persons' living with HIV/AIDS said:

> I was diagnosed after delivery and her child tested HIV positive. The child became very ill and died. Then, I got tested and was found to be HIV positive. Thereafter, my first child took ill found to be HIV positive and also died. My husband refused to be tested but sent me packing out of his home. Today, I have found a family and a community with this support group of persons living with HIV/AIDS.

From the diagnosis phase, the women became immersed and increasingly involved with the HIV community. At least once every month, they visit the hospital to listen to talks on HIV/AIDS, collect drugs when due, and to meet and interact with other members of the HIV community of PLWHA. Many reported that joining and participating in the HIV community has empowered them. They have found out that they are not alone and that AIDS is not a death warrant.
One woman noted:

> I thought before now that anyone told she had HIV, was going to die soonest.
>
> I had no hope of living long. I was not convinced that all was not lost at the time of my testing and being counselled. I feared for my life thinking my husband will kill me. But, I can tell you told that those were unfounded fears because I enjoyed support from family members and the HIV community. I am a farmer and three farms. The important lesson is that I must take my drugs, that are why today, I am unhappy because the Corper pharmacist is not here to dispense our drugs and I came from very far away.

Another woman noted: “my interest and desire to know more about HIV/AIDS and my confidence in disclosing my sero status to anyone who cares to know, and my conversation with others in the hospital to get tested and take their health into their hands endeared me to the matron, who subsequently and formally drafted me as a volunteer worker in the Heart to Heart Clinic. Ever since my diagnosis and coming to the hospital for treatment, I have devoted my life to working with PLWHA. I have been involved with this HIV community in sensitizing the public on HIV/AIDS. Many believed that I am not HIV positive. Rather, they say I am paid to do this work so are other members of the group”.

Another phase was making situational disclosure and at times to hit back at others.

> A woman was scorned, gossiped and laughed at by members of her neighbourhood on knowing that she had HIV/AIDS. Some said that she killed her husband by infecting him with HIV. However, on one of her visits to the hospital to collect her drugs, she met one of these neighbours who also came for her drugs. They exchanged pleasantry and left. She on reaching home, went to the other woman’s mother-in-law and told her, your wife also have that disease because we now meet where we go for drugs. The mother-in-law replied: I do not know what you are talking about. My wife is fine and is just having routine treatment for a sickness and not the same as yours.

The woman whose husband walked out of his parent’s home never to be seen is finally back to her family of procreation and has remained active in HIV/AIDS community. She reported that this Christmas holidays:

> Her younger brother called her and said that people were wrong when they said you had HIV. You look so well now that I know it was not HIV/AIDS. At this point she told her brother to seat on the bed. She then went and confirmed to her brother that those stories about my HIV status were correct and that she is really HIV positive but she can live a normal life as long as she takes her drugs. She then spoke to him of the importance in engaging in safer sex practices and not getting involved in risky behaviours such as sharing of razor blades, needles, or injecting drugs. I told him HIV is real but can be prevented.

Factors Facilitating Disclosure

In the process of narrating their stories, the women identified a number of factors that helped them to disclose their serostatus and also made them comfortable when talking about their HIV positive status and their coping mechanism. These factors included the followings:

Attendance in HIV services such as ante-natal clinics

Some of the participants (3) in the Heart-to-Heart support group noted that they got to know of their HIV status while attending ante-natal clinic. They reported that as part of their regime on their first clinic day is to receive a talk from the health providers, mainly nurses on HIV/AIDS. Thereafter, they were told that testing was necessary to continue their visits. Then, their consent is obtained and they get tested. Those of them who were HIV positive were further counselled and told that they can have HIV free babies if they adhered to the advice given during their visits.

One of these women noted that "she was advised to breastfeed only for three months, without water or any other source of milk. Or, do not breast feed at all. In addition, she said that for her to adhere to the option of breastfeeding only, she had to inform her mum of her serostatus and sought her support in keeping to this routine. Accordingly, her mum came to stay with her to make sure she adhered to the routine. By this action, her mum was not going to give the baby water in her absence or allowed anyone else to do so" (Female 29 years). She also boasted of having an HIV free baby and that she was at the clinic today to find out how she can have another HIV free baby.

Membership in HIV/AIDS support group

All the women reported that membership in the support group has empowered them to seeing a brighter future ahead. Most of them said, at the time of their diagnosis, they saw a bleak future and death knocking at their door. However, these participants noted that "since joining this support group I have others to identify with and they have given me hope of living a better life. I have learnt that taking my medications and following the advice given us give me quality life". Another participant reiterated that "before I came to this clinic I was so sick and very skinny. I thought I would die any moment. But, my adherence to my medication and eating well nourished meals has kept me strong. I have put on weight and look healthy. The rashes on my skin have disappeared. If I do not tell you I am HIV positive, you can never know from my physical appearance." (*Single woman, 32 years old*) A younger participant added that "my younger brother told me that people were lying when they said I had HIV infection during my prolonged illness, because I looked so well and active now."

Of great importance to all the participants is the fact that "we learnt from each other's experience in terms of coping strategies. In addition, we seek out each other, particularly if one fails to attend clinic days'. One participant noted that once of tem stopped coming and she contacted her on phone. The young lady told her she has re-located to Benin City and was living with her boyfriend. The lady also said she was not practicing protective sex. She tried to advise her but she persistently maintained she was no longer HIV positive. She also stopped taking her medication and she finally fell seriously ill and died" (*Female 28 years old).*

All the participants concurred that such cases straightened their desire to adhere to their medications and not to run out of medication. The participants further noted that "they were saddened today because the pharmacist, National youth service corp. member, is not around to give them their medicine. Their failure to get their medicine may jeopardize their health".

Knowledge of Partner's serostatus

Many of the participants reported that knowing their partner was HIV positive made insist on being tested for HIV virus. One of the participant, (female, 35 years old) noted that "my husband was sexually active and had multiple partners. I have complained continuously but he refused to desist or change his behaviour. Finally, he got very ill and could not work anymore. He went to the hospital and finally got tested. He was HIV positive. He shared the news with me. Both of us cried and I told him see what you have caused your family. Thereafter, I became ill and got tested and I was HIV positive too. Now he stays at home, keeps no woman outside. We have kept it from both our families. All we are doing now is to save for our children so they will not suffer when we die. I have strength to work so no one ever suspects I am HIV positive".

Need to Break the Culture of Silence

Most of the participants reported that their strong desire to curtail the spread of HIV virus in their community has informed their disclosure and participation in public rallies. They noted that anytime they organize a rally, the people do not believe they are HIV positive. In fact, the women said, some of the people who came out to listen to them would ask them "how much were you paid to label yourself so negatively? Even when we reply saying we were not paid anything but are saying the truth they fail to accept."

Further probing on why they chose to publicly disclose knowing the stigma and discrimination surrounding HIV positive persons, they strongly added that "there is urgent need to let the people know that HIV is not written on anyone's head. Therefore, it is difficult to ascertain an HIV positive person. Therefore, hearing from us would confirm this and further allow others to know that there is life after being HIV positive".

Factors Inhibiting Disclosure

Conversely, the women listed factors that inhibit the decision to disclose. These factors include the followings:

Anxiety and Denial

Many participants reported that their initial reaction on knowing their serostatus was to say "it's not possible. It must be a mistake. The laboratory technicians are incorrect and have not done the test correctly. Some added, "We went to more than three places to be tested and the results were the same. The next thing was "I do I keep this away from close friends and family members. The determination and decision not to disclose further heightened my anxiety. Many noted that they were visibly stressed but attributed their condition to other issues to prevent people from probing further.

AN elderly participant noted that “I was so stressed that I moved out of my husband’s home without giving him any reason”. She added that “moving out of my husband’s home has made it less stressful because I was terribly worried of my husband’s reaction when he knows of my status.” On further probing on what her husband reaction would have been, she said: “he may have beaten me to death and sent me empty handed to my family. Leaving my husband’s home on my own gave me ample time to take all my things with me”. She also added that “I never told him and will never do so”. However, “I am sure that my husband and co-wife caught it because both are hail and sound, and I have been confirmed HIV positive for five years”.

Fear of abandonment, Stigma and Discrimination

With these women, only one has failed to disclose her status to neither family members nor friends. She noted that “I am scared of them abandoning me. Or, my family members may isolate me, send me to the street or keep me away from interacting with them”. She added that occasionally, I sample their reaction by bring up the topic and many would vehemently respond that “I cannot live under the same roof with an HIV positive person because many things bout remains unknown. The last thing they wan t is to have such disease that has no cure. It would be too close home and shame will be our portion if other members of the community get to know. At a time, a member of the family said that I may put the laws into my hands and silently kill the relative irrespective of whether he or she is a brother or sister of the same parents”.

Nonetheless, additional motivators that further enhance the decision to disclose include the followings:

- Desire to reduce further transmission
- Accessibility to Support and care Services
- Willingness to prevent vertical Transmission
- Concern for others
- Counselling
- HIV Support Groups
- Dispositions and interpersonal relationships of Health Providers and PLWHA
- Deprivation and Poverty

Challenges Experienced by women with HIV/AIDS

The participants interviewed reported that they face a number of challenges which include issues of accessibility to treatment and care services, cost of transportation to the nearest place for treatment, the absence of a full-time pharmacist at the hospital, the depleting resources from the journey to be diagnosed as HIV positive, fear and abandonment by ignorant persons, attitude of the public to PLWHA.

Accessibility to Treatment

Most of the participants reported that the treatment centres are limited with only one serving three local government areas, namely Esan North East, Esan South East and Igueben. From these three geo-political areas, these participants have to travel long distances to see the physician and collect their medications. Yet, they noted that there are two central hospitals in the other two later local government headquarters (Ubiaja and Igueben). They queried, 'what are the factors and reasons for the absence of such treatment centres'. Many were quick to re-iterate that such "absence of treatment facilities tend to hinder disclosure and the need to be tested". Most of the women reported that being a member of the support group at Heart to Heart clinic in Uromi Central Hospital, brings them in contact with other PLWHA. Such contact gives them "a sense of not being alone, a feeling that all is not lost with the disease, and a community to rely on for support and assistance".

A participant said:

> I had met one of the participants at a friend's house when she was very ill. I wanted to ask her to go for testing, but my friend discouraged me saying the woman may react negatively or violently. One day, we met at the clinic and ever since, we have been in communication. My friend does not know that I am HIV positive. The woman is much better through her adherence to her medicine.

The common finding is that all the women believed they contacted the disease from their husband. The primary reason is that their earlier births were HIV negative except for the last baby.

CHAPTER SIX

DISCUSSION AND CONCLUSION

The data shows that all of the participants attending both UBTH and Heart-to-Heart clinic and are members of the support group felt safe to disclose and talk about their serostatus with the health workers, including physicians, counsellors because they were more likely to protect their identity because of the confidentiality and anonymity guiding their profession and practices. Earlier studies (e.g. Muula, 2005) have reported that health personnel were by their ethical and professional codes bound to keep confidential all information about their clients' health including PLWHA. Hence, PLWHA in this study and earlier ones felt confident that health professionals can be trusted.

Our data also bear credence to others studies (e.g. Moore & Williamson, 2003) that show PLWHA being discriminated against by family members. Hence, PLWHA may not feel comfortable disclosing their status to family members. Another reason for non-disclosure to family members was to prevent PLWHA and their families from being discriminated against in the community simply because of their own serostatus. Yet, disclosure to family members is known to reduce the burden of coping with the infection.

PLWHA, particularly those attending UBTH clinic tended to perpetuate a culture of silence around their serostatus by keeping their lips sealed rather than disclose their serostatus. This culture of silence evolved from personal experiences shown in this study that depicted family members such as a child abandoning her mother in the hospital bed after her disclosure and a sister openly announcing to the neighbours that her sister is HIV positive. In cases where disclosure has been made, some have regrets because they feel they are discriminated against by such persons. This finding has also been reported in earlier studies, such as the study in Lome, Togo which reported that disclosure to family members led to being discriminated against (Moore and Williamson, 2003).

This present study shows that disclosure to at least one parent was primarily the mother, which results from the fact that parent-child communication and interaction is limited in many African families, except between mother and child. Communication and interaction with father is limited to the later acting as a disciplinarian in the family, whose role is to keep the children on track and from deviating from family norms, values and expectations (Omorodion, 2010). 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 style adapted by most fathers (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. However, this finding is contrary to the findings in other societies, in which disclosure to significant others including parents and siblings is more prevalent than in the study. Existing studies also found that disclosure is often to those family members who are likely to provide care and social support, particularly in poor families (e.g. Holt et al., 1998). 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 (Federal Ministry of Health, 2004). Therefore, it is deduced that a wife with HIV infection must have contracted the virus from extra marital relationship and infidelity. This study 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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