

## **LIVED EXPERIENCES OF GHANAIAN WOMEN DIAGNOSED WITH HIV and AIDS**

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### **ABSTRACT**

Living with HIV and AIDS is a recent worldwide phenomenon known to be a distressing condition causing disruptions in interpersonal relationships between women and their significant others, families and society. This study describes the meaning of living with HIV and AIDS for 16 HIV-positive women using a phenomenological qualitative method. In-depth interviews were conducted with purposively sampled HIV-positive women between March and December 2008. The purpose of the study was to investigate the lived experiences of HIV-positive women and consequently to develop, implement and evaluate a non-government organisation (NGO) based support framework to meet these needs. Tesch's data analysis approach was used to synthesise a description of the women's lived experiences.

The findings revealed myths about methods of HIV transmission leading to negative public attitudes including stigmatisation, discrimination, humiliation, blame and rejection resulting in anxiety, suicidal ideations, low self esteem and sleeplessness. HIV-positive women's rights appeared to be often violated and legal aid services were inaccessible due to lack of privacy and confidentiality in court rooms. Parse's Theory of Human Becoming framed the researcher's theoretical perspective. The study concludes by emphasising the need for implementing HIV and AIDS anti-stigma programmes in Ghana.

**KEYWORDS:** HIV and AIDS myths in Ghana, HIV and AIDS in Ghana, lived experiences of HIV-positive women, HIV and AIDS stigma in Ghana

### **INTRODUCTION AND BACKGROUND INFORMATION**

Accra is the national capital city of Ghana and the seat of government. Accra has a total population of about five million people living in six sub districts (Ghana Statistical Service, 2000:10). Approximately 25.0% of the urbanised population in Ghana live in Accra. The greater Accra region, one of the ten regions of Ghana, has 84.0% of its population living in urban centres. There are diverse socio-cultural groups including

the Akan groups who constitute 44.0% of Ghana's population. The others comprise the Ga-Dangbe, Ewe and the northern tribes of the Mole-Dagbani and Guan.

HIV transmission occurs primarily through the heterosexual route (80.0%) (Ghana Health Service, 2007:49). The transition period from HIV infection to AIDS ranges from 2–8 years for adults and 1–3 years for children (Mills, 2007:176). Seven out of every ten persons living with HIV and AIDS in Ghana are women (Ghana Health Service, 2006:42).

## **RESEARCH PROBLEM**

Ghanaian women diagnosed with HIV and AIDS experience stigma and discrimination (Mill, 2003:17). The consequence of being HIV positive in Ghana is abject poverty, malnutrition and ostracism, rendering the woman unable to care for herself and her children. The experiences of women diagnosed with HIV and AIDS necessitate the development of an intervention programme for the reduction of stigma and meeting the needs of women. The first step in the development of an intervention is to explore the lived experiences of the HIV-positive women from their own perspectives. The research question for the study was therefore: What are the lived experiences of HIV-positive women in Accra?

### **Objective of the study**

The objective of the study was to explore the lived experiences of HIV-positive women in Accra.

### **Theoretical foundation of the study**

The study was based on Parse's Theory of Human Becoming. It was necessary to choose a theoretical foundation for the study to inform the role of registered professional nurses in exploring the lives of the HIV-positive women as well as their own emotional responses due to the participation in the study.

According to Parse, the goal of practice with the Human Becoming Theory is that the quality of life from a person's perspective cannot be determined by those not living the life. Thus the person is the only one who can describe his/her quality of life. This stems from the belief that people co-author their health. The basic factors that determine and promote people's quality of life include a healthy and clean environment, good socio-economic conditions that will promote good psychological and physical wellbeing of the individual. The theory focuses mainly on the lived experiences of the individual who can be considered as indivisible, unpredictable and ever changing as the individual makes choices freely after choosing meanings of situations in the environment. The main themes underlying the theory are structuring meaning with the concept of language, valuing and imaging (Parse, 1981).

## **RESEARCH METHODOLOGY**

### **Research setting**

The study was conducted in a HIV and AIDS non-governmental organisation (NGO) assisting women living with HIV and AIDS in the Accra metropolis.

### **Research design**

A qualitative phenomenological study design was chosen to explore the lived experiences of these women. Phenomenological studies examine human experiences through the narratives of the persons involved (Uys & Basson, 2000:52).

### **Population and sample**

The target population for the study comprised HIV-positive women residing in the Accra metropolis who were referred for support services to the NGO. Purposive sampling was used to recruit participants for the study. The criteria for inclusion were HIV-positive women, aged 18 years and older, and residing in Accra. The women had to be registered at the NGO. In addition, they were required to communicate effectively in Twi, Ewe, English or Dagaare and willing to participate in the study. The sample size was governed by saturation of data, which was realised when 16 participants had been interviewed.

### **Data collection**

To gain a full understanding of the lived experiences of the HIV-positive women, several qualitative data gathering methods were employed. These included in-depth interviews, field notes and a self-reflective journal. In-depth interviews are conducted as a conversation with a purpose. Through in-depth interviews, researchers strive to gain entrance into the informants' world to have full access to their lived experiences (Polit & Beck, 2008:227). The in-depth interviews were conducted with the use of an interview schedule containing a demographic section as well as a central question to focus the discussion. The second author conducted the interviews twice monthly from February to December 2008.

A pilot study was conducted with two HIV-positive women at the fevers' unit of the Korle-Bu Hospital. The results of the pilot study were that the interview schedule, the interviewing skills of the researcher and the data analysis approach were acceptable. No changes were made after the pilot study. The pilot turned out to be a reassuring experience for the researcher.

### **Data analysis**

The data analysis approach used was content analysis using open coding. The interviews were transcribed and read several times to identify recurring themes and patterns among the themes. Tesch's (in Creswell, 2009:183) data analysis approach was chosen. This involved breaking down the narrative data into smaller units, coding and naming the

units according to the content represented. The coded material was grouped on the basis of shared concepts and meanings. The themes were then categorised and exhaustively described, supported with verbatim quotes from the participants.

### **Trustworthiness**

In qualitative research, rigour or trustworthiness is most often a preferred term for reliability and validity as the methods for establishing reliability and validity differ from those used in quantitative studies (Brink, 2006:118). To meet the requirement of dependability in this study, the researcher recorded all interviews using an audio tape. The interviews were transcribed verbatim and field notes were compiled. Field notes and a self-reflection diary were kept regarding the interviewer's own bias, reflections, values, perceptions, feelings and decisions about the phenomenon and progress in the field. This conscious effort on the part of the researcher to "reflexively bracket" (Polit & Beck, 2008:748) her own experience was undertaken to prevent undue bias of the research process and the interpretations based on the interviews. The researcher used several techniques to achieve credibility including member checking, prolonged engagement, reflexivity, peer debriefing and structural coherence. Triangulation was achieved through the use of three data gathering methods, namely in-depth interviews, field notes and a self-reflective journal.

## **ETHICAL CONSIDERATIONS**

Approval for the study was sought from the Ethics Committee of the Tshwane University of Technology (Reference number: 2008/03/007) and Noguchi Memorial Institute for Medical Research, University of Ghana, Legon (reference number: DF. 22). Informed consent was obtained from each participant. Anonymity and confidentiality were maintained by not recording any respondent's name and keeping the verbatim records under lock and key. The interviews were conducted in private settings chosen by each participant at her convenience.

## **RESEARCH FINDINGS**

### **Participants' demographic profile**

The majority of the 16 participants were widowed (n=9) or divorced (n=2). Participants who were still married indicated that their spouses were also diagnosed with HIV and AIDS. All major socio-cultural groups in Ghana were represented, including the Mole-Dagbani, Dagaaba, Dagomba, Gonja, Kotokoli, Ga Dangbe, Ewe, Akan and Guan. The women's ages ranged from 21 to 61 (modal age 40 years). Only one participant was childless but the rest of the women had 3-7 children. Seven participants had never attended school, five had dropped out of school, two had completed junior secondary and middle school. Only two had acquired tertiary education. Most of the participants had

been economically active ranging from being self-employed to formal employment prior to the diagnosis of HIV. After their diagnoses, all the participants became unemployed because of recurrent opportunistic infections.

### Themes and categories generated from the study

**TABLE 1:** Themes and categories

Themes	Subcategories
Experience of being diagnosed with HIV and AIDS	HIV transmission role of the husband Diagnosed due to chronic illness and hospitalisation Experiences related to VCT and being HIV-positive
Barriers to disclosure of HIV diagnosis	Selective disclosure Perceptions of stigma and discrimination Emotional experience People's reactions to HIV AND AIDS disclosure Continued social participation Economic survival
Fear of symptoms of AIDS-related illnesses	Fear of weight loss Skin lesions Fear of getting diarrhoeal episodes
Perceptions, misconceptions and beliefs about HIV and AIDS	Myths regarding methods of transmission HIV and AIDS viewed as a spoiled women's disease ( <i>Muora</i> )
The psychological and emotional state of women diagnosed with HIV and AIDS	Anxiety Suicidal ideation Low self-esteem Sleeplessness Challenges associated with the HIV diagnosis Social isolation
Absence of social sanctions and ability to speak out against AIDS-related stigma and discrimination	Lack of access to legal aid and services Lack of privacy and confidentiality Fear of wider exposure

### Women's experiences of being diagnosed with HIV and AIDS

One of the major themes identified among the participants was the experience of being diagnosed with HIV and AIDS. The reason for being tested varied, some became sick, some underwent VCT of their own volition and some were diagnosed after their spouses

had been diagnosed with HIV. The participants experienced various reactions from significant others as indicated in the three subcategories generated. To provide rich data to promote understanding, some narratives are as follows: *“I never knew I had this disease. I became very sick and could not go to work ... I became very lean, thin and very weak. I was always going to the toilet (diarrhoeal episodes). Then one day the Director came and took me to the hospital and a test was done and I was found to have HIV and AIDS. I was very sad and knew that I was going to die.” “Oh no! I am shocked. I never ever dreamt I will get HIV. There was this thing ....a programme on the TV about VCT especially before marrying. So I made up my mind to go and test so that I will encourage my fiancé also to test because we were then planning to get married. I tested HIV-positive and my fiancé decided to abandon me due to my diagnosis with HIV and refused to undergo VCT.”*

### **Barriers to disclosure of HIV diagnosis**

The impact of HIV diagnosis on the social lives and economic activities of the participants was the driving force for the persistent refusal of most of the participants to disclose their HIV status. Several barriers existed to HIV and AIDS disclosure. The subcategories used to describe this theme include selected disclosure, perceptions of stigma, emotional experiences and quality of life versus longing for death, continued social participation and economic survival. Disclosure is by nature personal and individualistic. Some participants, after considering the circumstances around their social and interpersonal relationships within a highly stigmatising environment and the zeal to continue to engage in their social and economic activities, were unwilling to disclose either fully to the public or partially (telling relatives, friends or spouses).

They described their unwillingness to disclose and the wish for their continued social participation in activities such as trading for economic survival in phrases such as, *“I am hiding here,” “I am living in secrecy,” “Silence is the best”* and *“No one should know because the dirt can never be erased.”* The dirt here refers to the shame, disgrace and guilt feelings each participant encountered and the consequences stemming from public ridicule and stigma. The intention never to disclose was highlighted by the following statements: *“I have not told anybody about my diagnosis except my family for example brothers and sisters and my mum. I have been going to the fevers’ unit for my treatment. At times I miss some of the months of review because I have been hiding myself because I don’t want anyone to know about my status and last time the nurses at ... told me about this association and they referred me and encouraged me to join. But it is not easy for me because I feel nobody should know about me and this is my big secret.”*

Another woman indicated her desire to continue with the economic activity of selling for an income to enable her to continue playing her social role as a parent: *“At times I and the children sleep without food. So I am hiding my HIV and ... sell to people to get money to help myself. Most people don’t know that I am HIV-positive. Some people even*

*say they will never go in for VCT. It is better not to know ... if they know I have HIV, everybody will run away from me. Like my landlord will even eject me from his house. Nobody will buy whatever I sell. So I have to be hiding to enable myself to sell ... to take care of my children. If they know, my children will even be insulted with it."*

### **Fear of symptoms of AIDS-related illnesses**

The health of an HIV-positive woman depends on the condition of her immune status as well as factors such as nutrition, sanitation and the social environment including care and support. In the World Health Organization's (WHO's) staging of HIV-disease, clinical stage 4 is the severe symptomatic stage and opportunistic infections occur in the absence of antiretroviral treatment (WHO, 2005:26). During stage 4, the individual is prone to wasting, frequent diarrhoea, Kaposi's sarcoma, skin lesions, herpes simplex and/or herpes zoster.

The participants' knowledge and awareness about HIV and its progress into AIDS caused concern and anxiety. The most dreaded symptoms of AIDS-related illnesses included the fear of visible signs of AIDS such as severe weight loss, getting skin rashes and diarrhoeal episodes. One woman concealed her diagnosis to enable her to continue selling ... in her community and explained her worst fears about HIV infection:

*"What I fear about this disease is how I will become very lean and turn into a stick before dying. At that stage people see you as having AIDS. There is no way you can hide anymore. So for me, I am planning that the moment I get into the AIDS stage, I will take poison and die because I want to die with my flesh not to turn into a stick before dying. Even though I am worried about my children, I will have to do that."*

### **Perceptions, misconceptions and beliefs about HIV and AIDS**

All the participants reported experiences regarding Ghanaians' perceptions of HIV and AIDS as a disease caused by women through prostitution (prostitutes' disease) and other misconceptions. Relevant statements included: *"When you are a woman from my tribe, and you get HIV, people call you names. They call me lean legs madam. I am known as a prostitute, spoiled and loose woman. When I come by some food and I want to cook they tell me to cook my food outside the house, I am not allowed in the kitchen. When I wash my clothes they don't allow me to dry the clothes on the line, the chair that I sit on nobody wants to use it anymore and whatever I am doing nobody will come near me. They don't count me in their family activities but everyday comes with insults and insinuations and I am constantly reminded about my husband's death and how I killed him with AIDS and have infected all my children."*

*"You know, so many people are very ignorant about HIV and AIDS. Over there in my village, the people believe that if an HIV-positive woman touches your hand, you will definitely get infected. This is the reason why nobody wants to get close to me or my children. They also believe strongly that I have infected my husband and my children as well. So nobody wants to receive things from me or give me things because my hand may*

*accidentally touch theirs. Even at the compound house where I lived, I was not allowed to use the same bathroom or cook in the kitchen (looking miserable and dejected)."*

### **Psychological and emotional distress of women diagnosed with HIV and AIDS**

The theme psychological and emotional distress stems from the way society views women who are diagnosed with HIV. The stigma and discriminatory attitudes of people towards the participants resulted in the development of various negative impressions and feelings. This caused suicidal ideation, social isolation, sleeplessness, low self-esteem and challenges associated with the diagnosis. Emotional upsets consisted of feelings such as sadness, being worried all the time, grief and despair low self-esteem and anxiety.

Most participants were sad, shy and embarrassed because they had contracted a disease that society labels as "bad." Worries according to most of the participants, stemmed from always thinking about the disease, its outcome and the shattered future plans and hopes for their children. Some were also worried about the possibility of other people knowing and the effect that this would have on their children after they had died. The participants also narrated the feelings of not knowing what to do, worthlessness and not being part of this world. Some felt that their lives had come to an end and they could only thing struggle to die.

One elderly woman explained: *"I am worried in case I also die, who will care for my children? So I do not sleep. In the night, it is a problem that I am always thinking about it. If I am walking about naked and my children get food to eat, it is better than anything else for me on earth. My husband's brothers don't care about me and the children. One of the children was admitted in the hospital and they never visited him."*

### **Absence of social sanctions and ability to speak out against AIDS-related stigma and discrimination**

There was an apparent lack of sanctions against stigma and discrimination against women living with HIV and AIDS. The lack of sanctions and avenues for social support systems is embodied in statements such as, *"lack of access to legal aid services", "no law will work", "no privacy and confidentiality in the court rooms."* The lack of trust in law enforcement agencies to enforce the rights of HIV-positive persons and to shield them from further exposure was expressed by the participants. A woman who was not employed due to her HIV-positive status, lamented: *"No! No! It will rather worsen my plight. Eh! Who am I to go about reporting people? If the people don't want me what else can I do (in a very sad mood). You see, the more I pursue these things about discrimination, the more I am exposed to the public. Now the whole community will get to know about me and my name will be on people's mouths that I reported officers about being discriminated against with employment. When that happens, then I better end my*

*life and rest! I am only praying to get money so that I can open my own ... services. If people get to know about my diagnosis in the area where I sell, nobody will buy!"*

## **DISCUSSION ON THE LIVED EXPERIENCES OF HIV-POSITIVE WOMEN**

Experiencing the diagnosis of being HIV positive was a very negative experience for the participants. Unless the stigmatisation, misconceptions and cultural inhibitions are reduced, an infected Ghanaian woman's life will not be worthwhile. For them, not knowing and not being suspected were far better than knowing. Advocates of VCT and early diagnosis must therefore take cognisance of the life-shattering effect the positive diagnosis had for these women and their children. Advocating diagnosis and disclosure without taking the cultural situation of the person into consideration must be questioned.

From a public health point of view, disclosure can benefit the public by reducing the transmission of the virus. However, from the HIV-positive person's social point of view, many negative implications became a reality. In the study, some of the participants selectively disclosed their HIV status to significant others, especially their families. Ironically, negative reactions were received from close family members. This finding of negative responses from family members seems to be partly consistent with that of Kalichman et al. (2004:320) who found patterns of selective disclosure with most participants disclosing to family members and significant others. The rate of disclosure was associated with social support and siblings were more supportive than extended family members.

Another relevant finding of the current study was the concern of the participants regarding their overall functional ability and control over symptom intensity. Most participants were on antiretroviral therapy (ART) medication but could not afford to take ART regularly due to poverty. Participants were therefore concerned about developing AIDS and feared the visible signs of AIDS-related illnesses. These findings support those of Phaladze et al. (2005:123) regarding the overall functional ability of the HIV-positive person. The participants in the current study believed that these visible signs and symptoms constituted AIDS and would reveal their concealed HIV diagnosis.

The finding on stigma and discrimination in the current study is consistent with reports on stigma worldwide (Mill, 2003:16; Poku et al., 2005:344; Li et al., 2009:26). The intention to commit suicide was mentioned frequently by the participants. The advent of ART might account for the lack of reported suicidal ideations elsewhere in the world while in Ghana, the scarcity of ART could account for desperate frustrations amongst people diagnosed with HIV.

The perceptions and misconceptions regarding HIV transmission are consistent with literature reports. The ignorance or denial of the male partners' role in the transmission of HIV is a serious concern. The WHO report on new HIV infections in 2005 confirmed

that most women were infected by their husbands or partners (WHO, 2007:3). Negating the role of the husband is a pattern in the Ghanaian culture, influencing the relationship between society, health and the environment. The perception of HIV and AIDS as a punishment from God in Ghana, has been documented (Awusabu-Asare et al., 2004:13) but was not disclosed during the current study.

Psychological and emotional disturbances including worrying, anxiety, depression, sleep disturbances and suicidal tendencies were prevalent amongst the participants. Suicidal ideation was reported frequently by the participants. For most participants, the decision to commit suicide was based on their desire to conceal the HIV diagnosis. In committing suicide, the participants' death could maintain the secret of the diagnosis to safeguard their children from stigmatisation. In death, they would be respected during the performance of the funeral rites and arrangements because death from a stigmatised disease such as AIDS is abhorred (Kalichman & Simbayi, 2004:64; Mawar et al., 2005:473). From a clinical perspective, psychological and emotional distress is associated with worse clinical outcomes among HIV and AIDS patients even in the era of ART (Moskowitz, 2003:623).

The study provided some evidence regarding the lack of social sanctions and ability to speak out against AIDS-related stigma and discrimination issues. This resulted in HIV-positive women not having the courage to seek legal aid or other social services. Their reasons related to a lack of privacy and confidentiality and the fear of wider exposure in society. Honermann and Berger (2008:33) stated that the use of litigation and legal services protects and advances the rights of people living with HIV and AIDS. Though on paper the right existed, in reality the women did not have positive experiences with these available legal options.

## **CONCLUSION**

Being a woman with an HIV-positive diagnosis in Ghana has severe consequences. Contrary to current best practice, the women concealed their diagnosis to the bitter end. The findings revealed that HIV-positive women encountered numerous social, economic and psychological problems including stigma, discrimination, ostracism and social isolation. A question must be raised regarding the culture of “disposing” of women who became positive, mostly not by their own actions. These women's plights would not be lessened without intensive efforts to inform the population, breaking down stigma and discrimination, raising awareness and formally through legal pathways.

## **RECOMMENDATIONS**

Based on this study's findings, and the suffering reportedly experienced by HIV-positive women (and their children) who disclosed their HIV status, caution should be exercised in advising women to disclose their HIV-positive status. Health care policies, advocating

disclosure of HIV status, should be based on knowledge and understanding of cultural, social and individual circumstances. Once a person's HIV status has been disclosed, it can never be reversed. For many African women disclosure of being HIV-positive, could be a death sentence. The severity of being a social outcast, of not being touched by any one, of being unable to find a job or earn money to sustain one's children, caused some women to consider committing suicide. By encouraging disclosure of being HIV infected, health care workers could impose death sentences on women in some communities. Thus the emphasis on disclosure should be re-considered for specific communities, cultures and individuals' circumstances.

## LIMITATIONS

The study's findings are based only on qualitative interviews conducted with 16 women using the services at one NGO centre in Accra, Ghana. The experiences of these 16 women might be different from those of women living in other areas in Ghana, and/or women who did not use this NGO's services. All information was obtained during in-depth interviews, no observations were done and no correlations with the women's health/medical records were done. The women's narratives were accepted as the portrayal of their lives' experiences. Thus the conclusions of this study need to be interpreted against these potential limitations.

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