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The experiences of people living with HIV/AIDS in Gaborone, Botswana: stigma, its consequences and coping mechanisms

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Background: This study was carried out in Bontleng, Extension 14 and Old Naledi, which are low-income residential areas of Gaborone, Botswana. The aim of the study was to explore the experiences of people living with human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). The study was an attempt to discover the experience of the lives of people living with HIV/AIDS (PLWHA) and how they coped living with the infection.

Method: This was a qualitative, phenomenological, cross-sectional study. Fifteen participants were selected by purposive sampling, and gave their consent for face-to-face, in-depth, audiotaped interviews. The interviews were transcribed and content analysis applied to the transcripts.

Results: The diagnosis or manifestation of HIV/AIDS led to external and internal (self) stigmatisation, which seemed to manifest in ways peculiar to the Botswana context, and affected almost all areas of the lives of PLWHA. Stigmatisation and the progression of the disease led to psycho-emotional disturbances, job losses, poverty, dependence, moving in with relatives, concerns about children, the strain or disruption of relationships and painful bodily symptoms. Participants wanted to be gainfully employed as soon as their health improved, and detested having to depend on other people and organisations for their needs. They found the emotional support of other PLWHA to be more meaningful than counselling by healthcare workers. Religion was used by some to cope with life as an HIV-infected person.

Conclusion: Internal and external stigmatisation seemed to characterise the experience of participants. Stigmatisation negatively impacted on the lives of PLWHA, as well as strategies to combat the HIV/AIDS epidemic. Stigmatisation needs to be prevented at all levels. PLWHA have needs that require interventions that address their special circumstances.

Keywords: Botswana context, community-based coping strategies, external stigmatisation, internal stigmatisation, poverty alleviation, stigmatisation

Introduction

There are 34 million people living with human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) worldwide.¹ Most people living with HIV/AIDS (PLWHA) live in Africa,^{1,2} and in 2011, the highest death rates from HIV/AIDS were in Africa south of the equator. PLWHA live in settings that are largely poor in resources in Africa. Even when free antiretroviral therapy (ART) is available for eligible patients, drugs are often not accessible because of logistical, financial or institutional constraints.³

Besides the suffering caused by the disease, PLWHA have other challenges to overcome, including being stigmatised. Stigmatisation has persisted despite improvements, as a result of ART, in the quality of life and life expectancy of PLWHA.^{3–9} Stigmatisation is a process whereby unequal power relationships are used to label, stereotype, separate, lower the status of and discriminate against others.¹⁰ Through stigmatisation, PLWHA often become objects of scorn, hatred, violence and death.^{7,8,11} Self or internal stigmatisation also occurs, and leads to depression and low self-esteem,⁶ which may cause PLWHA to be wary of being around other people because of fear that their HIV status will be discovered.¹² Many PLWHA disclose their status in Nigeria and South Africa, but 40% do not because they fear being rejected and because counselling did not improve the ability of non-disclosers in Nigeria to provide disclosure.^{13,14} This worsens the HIV/AIDS epidemic as non-disclosers are likely to have multiple partners, HIV-negative partners, partners of unknown HIV status and unprotected sex.¹⁴ External (by others) and internal

(by self) stigmatisation also compromises HIV/AIDS interventions, including voluntary counselling and testing, assessment and monitoring for ART eligibility, and ART adherence.^{3,8,15}

Stigmatisation and ill health may lead to workplace problems and loss of jobs.³ This has implications for access to accommodation, treatment and food security for the breadwinner and his or her family. Poor nutrition accelerates the progression of HIV/AIDS.

Churches are usually places of comfort and support for the marginalised, but at times they are judgemental and their members show stigmatisation towards PLWHA.⁷ Churchgoers may believe that PLWHA are being deservedly punished by God for their sins, and they sometimes view PLWHA as indecent.⁴ A negative attitude towards PLWHA can also compromise efforts to contain the pandemic.⁹

The effect of HIV/AIDS on communities weakens efforts to counter the epidemic.^{9,16} The productive workforce is diminished, and food resources dwindle as breadwinners become too ill to work or die. Money to obtain treatment or for transport to treatment sites becomes scarce, and the extended family and other support mechanisms may be inadequate.¹⁶

HIV/AIDS distorts communities and families as it may promote the rural-urban migration of HIV/AIDS widows to seek employment or their husbands.¹⁶ Patients often go to their villages to die, and families disintegrate as children are fostered to different relatives. Other families become dysfunctional

because the older children become head of the household and have to take care of themselves, their siblings and elderly grandparents.¹⁶

Although many PLWHA are in good relationships, HIV/AIDS sometimes causes the loss of spouses or strained relationships.^{8,9} Loss of intimacy may occur and safe sexual practices raise the suspicion of infidelity and are thought to be less satisfying sexually.⁹

PLWHA are prone to depression and anxiety⁶ and may suffer from neurological diseases that affect cognition. The loss of mental capacity can cause anxiety.

Stigma and the other experiences of PLWHA are social constructs.¹⁰ These constructs are experienced, understood and practised differentially according to the dictates of different contexts. The purpose of this study was to explore the experiences of PLWHA in Gaborone, Botswana. As far as we are aware, this is the first study to focus specifically on an exploration of the experiences of PLWHA in Botswana. Locally applicable interventions help with communities' coping strategies, and are therefore important in the fight against HIV/AIDS.⁹ Studies such as this one may help to provide the requisite local evidence base for contextually relevant interventions.

This study was carried out in Bontleng, Old Naledi and Extension 14, which are low-income, high-density areas of Gaborone. Participants were recruited from a nongovernmental organisation (NGO) hospice, from a PLWHA support group NGO run by PLWHA, and from a church. It was performed in 2007, in the early stages of the implementation of universal free ART for eligible HIV/AIDS patients in Botswana. During that time, many AIDS patients were not on ART, and AIDS was still a disease that resulted in death within a few months. Funerals were commonplace in Botswana because of high mortality rates as a result of HIV/AIDS, which was then, and still is, a dreaded disease in Botswana. The study remains relevant because attitudes towards PLWHA, and the feelings experienced by the latter, may affect whether or not PLWHA access ART drugs, and the extent to which they present for testing.

Aims and objectives

The aim of the study was to explore the experiences of PLWHA in Gaborone. The objectives were to understand what their lives were like, what they experienced and how they reacted to these experiences.

Method

This was a qualitative, phenomenological, cross-sectional study. The study population was PLWHA who were clients of the Holy Cross Hospice, Matlo Go Sha Mabapi and Old Naledi Baptist Church in Gaborone, Botswana.

Sampling was non-random and purposive. Fifteen participants were recruited from these three sites, which are situated in high-density, low-income residential areas of Gaborone.

A senior employee at the hospice identified suitable participants for the study. Members of the PLWHA-run NGO, who were present one afternoon, were interviewed. Members of the church were identified by the pastor as being HIV-positive. Participants were asked to participate in the study and they agreed to be interviewed and for the interview to be audiotaped.

Inclusion criteria were PLWHA aged 18 years or older, living in Gaborone, at different stages of HIV infection and disease, who were well enough to answer questions for themselves, and

PLWHA who freely gave their consent to be interviewed. PLWHA who did not meet these conditions were excluded from the study.

In-depth interviews were conducted in Setswana, after the collection of demographic data. The following questions were used to guide the interview and reflection. Feedback and summarising were used to elicit detailed responses to each question:

- "Tell me about your life since you found out that you have HIV/AIDS."
- "How has your life been since you found out that you have HIV/AIDS?"
- "How would you describe your life?"
- "Describe how you feel?"
- "Tell me how you interact with other people in this community?"
- "How are you managing since you became aware that you have HIV/AIDS?"

This iterative questioning was helpful in obtaining in-depth accounts of experiences. The interviews were conducted to saturation and transcribed by the interviewer into English.

Content analysis was used to thematically analyse the transcripts. As interviews were being conducted, commonalities of experience began to emerge, and when the transcripts were read and re-read, common experiences became apparent. These common experiences were ascribed different colour codes, and each transcript was analysed using these colour codes. The colour codes were grouped and regrouped into themes. Two other people contributed to this analysis.

The requirements of the Human Research Ethics Committee at the University of the Witwatersrand and the Health Research Unit of the Ministry of Health in Botswana were met. Participants provided consent to be interviewed and for the interviews to be audiotaped.

Results

Fifteen PLWHA were approached and agreed to participate in the study (interview data coded A1–A15). There were 10 women and five men. Their ages ranged from 28–47 years. Eleven had children. One of them had lost all of her children, most probably to HIV/AIDS. Fourteen of the participants were unemployed. Twelve said that they had lost their jobs because of HIV/AIDS (most because of illness, but some owing to stigmatisation). Some participants accepted short-term jobs whenever they could find them. The experiences of PLWHA were complex, but stigma was the central theme throughout. Figure 1 is a summary of the themes that emerged.

Stigma

Stigma underpinned most of the experiences of the PLWHA. PLWHA were considered to be nauseating, dirty and undesirable in the eyes of others, even their siblings: "When they asked which plate I had used, or when they asked where the plate I had used was, it showed that they were not going to use it", said A11. Their status was also diminished: "We people with HIV, if you compare us with people, you would think that we are not people", said A10. A12 had experienced being detested: "Being despised (by other people) also has its part".

Psychological, emotional and psychiatric problems

Stigmatisation resulted in psychological, emotional and psychiatric problems. Depersonalisation turned PLWHA into people with an HIV/AIDS label. It is like "leaving this world to enter

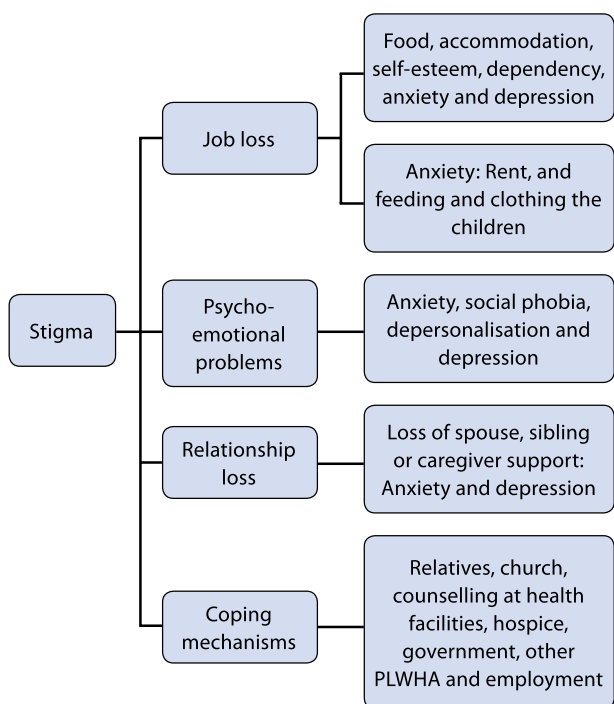


Figure 1: The everyday experiences of people living with HIV/AIDS in Gaborone, Botswana.

a new world" said A14. "I am unable to be my natural self. I have changed somehow," lamented A12. Stigmatisation by a doctor worsened the depersonalisation: "I left his consulting room crying. I asked myself, this man, does he mean that if I am positive, like this, I am not a human being or I am a prostitute?" said A13.

Pre- and post-test counselling did not prevent the anxiety associated with a positive test result. A1 reported: "You know, you are counselled first. I was telling myself that I had accepted myself, i.e. my status. But later, after the results were out, it started that at night when I am supposed to sleep, I could not sleep because I would start thinking a lot".

A14 recalled: "Even if you have been counselled, are told that you are positive, thoughts come. When they start and say, 'You are HIV-positive', you will start blaming, denying, feeling ashamed, asking yourself where you got the germ, blaming. You start now recording how many people you have had sex with". PLWHA worried about the future of their children and about possible death from HIV/AIDS: "I thought about my children. My children are three. All of them depend on me. So I thought really if I leave them and die", cried A15. A10 said: "I thought I was really dead. I thought I was going to die".

Social phobia, self-stigmatisation and depression manifested. PLWHA were afraid that it would be discovered that they were HIV-positive: "You see, you despise yourself. Then you become afraid of people. You fear communicating with people, you fear being in the midst of people", said A12. "Before I got ill, I liked a fast life, grooving, but now I have changed. I just stay at home," said A9. "I just spent all my time in the room, feeling pain and sleeping all the time. It was not because my body was painful. No. It was just that I had stress," recalled A13. Delusional thinking and paranoia were some of the experiences of PLWA. "...we people with HIV, if you compare us with people, you would think that we are not people", said A12. Friends who visited him were not genuinely interested in his welfare, said A15, "my mind tells me that they have just come to see how I am suffering (how this disease is)".

Job losses

Twelve participants reported that they had lost their jobs because of stigma and illness. A15 said: "They refuse to employ me now. If someone is living with the germ, it is not common that they can hire him". A4 reported: "I do not work. I left the job because of ill health".

Losing a job rendered the participants dependent on relatives, the hospice, church and government for sustenance and shelter. They could no longer support themselves or their children, and they suffered from hunger. Most lost their homes and lived with relatives.

A2 said: "Now if there is no job, there is nothing. Like now, there is nothing I have. My children also go hungry. So it means it is just problems". A8 lamented: "You know, I have at times shed tears because I strongly wish I was working now". Some PLWHA felt that finding a job would solve most of their problems. "I wish I could get a job. This is the help that would satisfy me. My desire is that I should work with my hands (be gainfully employed), not depending on anybody", said A13.

Broken relationships

Stigmatisation affected caregiver-participant relationships, friendships were strained, and some spouses left when their partners were diagnosed as HIV-positive. A11 recalled: "All things got spoilt. Even the father of my children left". "I would say that since I got ill, friends get out of you. Friends leave and you start living your life alone," said A1. Caregivers and PLWHA had strained relationships: "Now you see if a child is helping you, at the end, a time comes when it's like the child gets tired. So I stayed with a painful heart", said A6.

Descriptions of illness

The participants provided graphic descriptions of the HIV/AIDS illness experience, including breathlessness, paralysis, cramps, rashes, being tube fed, being unable to speak and feeling like death was imminent: "I had fever, difficulty in my breathing and feeling cold. I thought it was only flu", said A11. "Like I could not walk, my toes were curled up like this, I was not speaking. My teeth were tightly clenched. They fed me very thin porridge with a tube," said A5. "I had difficulty breathing. I had to breathe with painful heaviness, and had difficulty in breathing with the sharp pain blocking."

Thus, the bodily manifestations of HIV/AIDS contributed to the anxiety of PLWHA.

Coping with living with HIV/AIDS

The PLWHA coped with their situation by depending on God, and other PLWHA: "He (God) is the one who shall cure this disease at the time He cures it", said A5. "Before, I just spent all my time in the room, feeling pain and sleeping all the time. Now, since I met with people from this organisation, we spend time together, chatting and visiting ill people," said A13. The company and support of other PLWHA was valued considerably more than counselling by health workers.

Some PLWHA felt that finding a job would solve most of their problems: "I wish I could get a job. This is the help that would satisfy me. My desire is that I should work with my hands (be gainfully employed), not depending on anybody", said A13.

Discussion

Stigmatisation (self and external) of PLWHA was initiated by the diagnosis, disclosure or manifestation of HIV/AIDS (Figure 1), and it was common for participants in this study, as has been found in Nigeria, Malawi, Zimbabwe and South Africa.^{3,7-9} Stigmatisation

needs to be eradicated because it hampers efforts to fight the HIV/AIDS epidemic.¹⁵ PLWHA who did not disclose their status in Nigeria and South Africa because of fear of stigmatisation, as well as rejection, practised unprotected sex, had unprotected sex with HIV-negative people and also had multiple partners. Stigmatisation might result in a similar scenario in Botswana, and this would increase HIV infection rates. Stigmatisation and fear of rejection also compromise HIV/AIDS interventions, as shown in studies in Malawi, South Africa and Nigeria.^{3,8,15} HIV/AIDS interventions in Botswana would be similarly affected, and this would exacerbate the HIV/AIDS epidemic and increase the high cost of free national HIV/AIDS treatment. Therefore, it is disturbing that stigmatisation seemed to characterise most of the participants' everyday experience, as well as occupying a large part of their lives.

Thirty years after the onset of HIV/AIDS, stigmatisation of PLWHA persists in both developed and developing countries.^{3,5,6,9} This suggests that anti-stigmatisation efforts have been ineffective. Operational research is needed to find effective anti-stigmatisation strategies that will have an impact at grassroots level. In Botswana, stigma has been shown to manifest at family, health facility and community level, perpetrated by health workers, among others.¹⁷ A participant in this study described a stigmatising experience with a doctor. This has serious implications on the health-seeking behaviour and adherence to treatment by PLWHA. Thus, education against stigmatisation is needed at family, community and healthcare worker level. Also, in this study, PLWHA either isolated themselves or were reportedly concealed by relatives because of fear of stigmatisation, similar to the social phobia reported by women living with HIV/AIDS in London.¹² Apprehension about being with people, which results from fear of being discovered to be HIV-positive, affects voluntary counselling and testing, health-seeking behaviour, ART adherence and the overall battle against the HIV/AIDS pandemic. Thus, the promotion of efforts to counteract stigmatisation is crucial.^{8,9,18,19}

Most of the participants in this study were women, who were probably in unequal sexual relationships because of financial reasons. This inequity may have exposed them to an increased risk of acquiring HIV infection and post-infection depression, both likely to accelerate the progression of their disease, as well as their chances of infecting others.^{20,21} Presently, almost all children in Botswana are provided with primary education, while most of them receive secondary education as well. This should equip children, especially girls, to be employable or self-employed as adults, so as to minimise their dependency on men for financial support.

Illness and stigmatisation led to job losses for the participants, which is common for PLWHA,³ and may have worsened their anxiety and depression. Job losses and disease progression made participants and their children dependent on relatives, as has been found in other studies.^{9,16} This may have strained extended family relations because of the further distribution of meagre resources and caring for patients with a deadly infective disease for a long period.

The somatic manifestation of the disease may have been unsightly and abhorrent, leading to stigma and resulting in the disruption of caregiver and spousal relationships.²² It has been shown that HIV/AIDS has led to PLWHA becoming despised objects of scorn, and has sometimes even resulted in PLWHA being attacked or killed.^{7,8,11} Fortunately, as far as we know, spousal violence has not been a feature of the Botswana epidemic, and this may be because there is a culture of solving problems through dialogue, rather than physical means, within the country. The desertion of

PLWHA by spouses, as well as caregiver fatigue, are areas that need attention as HIV/AIDS interventions should build on existing support systems in order to optimise their effectiveness.⁹

The study participants' psycho-social problems were similar to those reported in other studies.^{6,8,23} The progression of the disease and the ability to infect others may have generated anxiety, depression, external stigmatisation and self-stigmatisation for the study participants.^{5,6,20,23} However, this study revealed how HIV/AIDS, depression, social phobia, anxiety, delusional and paranoid thinking manifested in this context. In Botswana, the fight against HIV/AIDS stigmatisation and self-stigmatisation should target people's fear of sharing food, amenities and utensils with PLWHA. Efforts to minimise stigmatisation must target caregivers and health workers as they are sometimes the perpetrators of stigmatisation.⁵ Few prominent PLWHA in Botswana have openly disclosed their status. They should be encouraged to do so as they have access to a wide social network, and familiarisation with PLWHA reduces stigma.^{5,7,8} Stigma could also be reduced by crafting HIV/AIDS education which presents HIV/AIDS as a chronic controllable disease.⁸ This may help because stigmatisation persists in Botswana despite the advent of HIV/AIDS treatment and improvements in the health of PLWHA as a result of ART.²⁴

The study participants used other PLWHA, relatives, friends, the church, as well as NGOs and the government, to cater to their emotional, physical and other needs. It is interesting that the support of other PLWHA was seen by participants as being the most meaningful. Religion, relatives and community structures are known coping mechanisms for PLWHA, and these interventions need to be encouraged.^{3,7,9,16} Caregiver fatigue and limited resources may reduce support for PLWHA. PLWHA support groups are more appropriate and may be sustained at a lower cost to government and donors.

Stigmatisation (and physical weakness) resulted in job losses, as documented in other studies.^{3,25,26} The Botswana government runs programmes to help people to become self-sufficient. These programmes could be adapted to target PLWHA so that they can become gainfully employed as soon as they are well. Employment was very important for most well PLWHA as it ensured that they were self-reliant and independent. Women need special attention because they tend to be economically weaker than their male counterparts. There are more women than men in Botswana,²⁷ and they support both the children and elders in many single-parent households. A self-sufficiency program for women living with HIV/AIDS may help lower HIV infections that result from women being dependent on men for financial support.

The disruption of relationships was reported in this study, as it has also been in others.^{8,9} Couple counselling for those who are HIV-infected, healthcare worker anti-stigma education and caregiver support programmes are interventions that government, communities and NGOs should consider to alleviate disruptions to relationships due to HIV/AIDS.

Counselling, as presently provided in health facilities, was insufficient in this study in dealing with the experiences of PLWHA. This has also been demonstrated in Nigeria and South Africa.^{13,14} The PLWHA-run NGO seemed to be better placed to deal with the experiences of participants in this study. Similar PLWHA support groups should be encouraged and supported so that they can complement the HIV/AIDS work of voluntary HIV testing and counselling centres and other agencies. The work of religious groups was very important to PLWHA in this study. This work should also be encouraged and supported.

Conclusion

Stigmatisation was at the core of most of the experiences of PLWHA in this study. It was common, it manifested in ways peculiar to the Botswana context, and it was seen at family, community and health facility level. There is a need to develop targeted and contextually sensitive anti-stigmatisation messages that are effective in minimising the HIV/AIDS stigma. Failure to minimise stigma effectively compromises the successfulness of HIV/AIDS interventions, and makes it difficult to combat the HIV/AIDS epidemic.

Locally appropriate interventions to minimise HIV/AIDS stigmatisation may strengthen community and government responses to the HIV/AIDS epidemic. It is hoped that relevant interventions will improve the lives of PLWHA in Botswana.

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