



HIV/AIDS Stigma in Botswana: Implications for the Dignity of People Living With HIV/AIDS

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ABSTRACT

Discriminating people living with HIV/AIDS not only causes personal suffering and loss of dignity, but it also contributes directly to the spread of the epidemic (Kumar and Kumar, 2007). Research findings presented in this paper are based on a research that was conducted between July 2007 and July 2008 through a series of focus group discussions, informal interviews and key informant interviews with 137 participants from Gaborone and four small villages in the southern region of Botswana. The purpose of the research was to investigate various descriptions used in Botswana to refer to people living with HIV/AIDS and to determine the implications of such descriptions for the dignity of people living with HIV/AIDS. The findings of this research indicate that stigmatising people living with HIV/AIDS challenges respect for others, as it renders an individual unworthy of full inclusion and participation in the community. This paper concludes that since HIV/AIDS related stigma denies people living with HIV/AIDS basic human rights to dignity, it contradicts Botho (Ubuntu) among Botswana. This in turn challenges the Religious Education educators to specifically emphasise attitudes of tolerance, compassion and caring among learners.

Keywords: HIV/AIDS; Stigma; Descriptions; Dignity; Botswana

INTRODUCTION

One of the greatest challenges to Education for Sustainable Development in Africa is the spread of HIV/AIDS (Lotz-Sisitka, Olvitt, Gumede and Pesanayi, 2006). On a related point, Nkomazana (2007) observes that HIV/AIDS is the biggest world killer and Botswana is one of the Sub-Saharan countries hardly hit by the epidemic. Thus, though HIV is preventable, it has remained the most devastating disease syndrome humanity has ever encountered. In many ways, stigma has been identified as the

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greatest obstacle in the prevention of the HIV virus and treatment of people living with HIV/AIDS in Africa (Amanze, 2007). For instance, the findings of the study conducted by Uys, Chirwa, Dlamini, Greeff, Kohi, Holzemer, Makoe, Naidoo and Phetlhu (2005) in five African countries: Lesotho, Malawi, South Africa, Swaziland and Tanzania on Descriptions of HIV/AIDS in Africa reveals that stigma attached to the illness is reflected by the various descriptions used to refer to people living with HIV/AIDS (PLWHA). Another related study conducted by Mawadza, (2004) on Stigma and HIV/AIDS discourse in Zimbabwe among 35 Shona first language speakers reveals that one way that language can be stigmatizing is in the use of derogatory references to PLWHA. Central to Mawadza's argument is that in general, words with negative connotation to describe HIV/AIDS form part of daily conversation in Zimbabwe.

Apparently, HIV/AIDS-related stigma in Botswana is prevalent at both individual and community levels (Amanze, 2007). In general, this stigma, which is mainly perpetuated by incorrect knowledge about HIV/AIDS, fear of death and certain religious beliefs leads to loss of identity, a sense of personal efficacy, discrimination and negative treatment (Togarasei, Haron, Jensen, Nkomazana, Mmolai and Sebina, 2008). The findings of a study conducted by Letamo's (2003) on Factors associated with HIV/AIDS-related Stigma in Botswana revealed that HIV/AIDS stigma creates circumstances that promote the spread of HIV/AIDS in Botswana. Letamo's study further revealed that HIV/AIDS stigma remains the greatest challenge in community mobilisation against HIV/AIDS.

In this paper, I first provide a brief literature review of HIV/AIDS stigma and dignity. This is followed by an outline of the methodology employed in this study. The paper then discusses the findings of this study and concludes by highlighting the implications of this study for the teaching of Religious Education in Botswana. It is hoped that the paper will offer a new dimension to the literature on HIV/AIDS-related stigma in Botswana, particularly descriptions of PLWHA.

HIV/AIDS Stigma and Dignity: A brief Literature Review

The term dignity is defined as "the state of being worthy of honour or respect" (The Oxford Encyclopedic English Dictionary, 1991:403). Dignity can also be defined as the quality or state of being worthy, honored, or esteemed. When this concept is associated with the adjective "human", it is used to signify that all human beings possess inherent worth and deserve unconditional respect, regardless of age, sex, health status, ethnic origin, political ideas or religion. In other words, this respect is owed to every individual by the mere fact that he or she is a member of the human family. In this way, individuals lack dignity when they are in situations where they feel foolish, incompetent, inadequate, vulnerable, or not in control of their circumstances. Stigma denotes differences and a stigmatised group suffers discrimination (Foremen, Lyra and Breinbauer, 2003). This discrimination

argues Foreman et al, is characterised by rejection, denial, discrediting, disregarding and underrating. As observes Gilmore and Somerville (1994), stigma is most frequently associated with diseases that have severe disfiguring, incurable and progressive outcomes, especially when modes of transmission are perceived to be under the control of individual behaviour. According to Gilmore et al, stigma is also common in diseases that are perceived to result from the transgression of social norms, such as socially-sanctioned sexual activity.

HIV related stigma can be defined as prejudice and discrimination directed at people perceived to have HIV or AIDS (Emlet, 2006). The already mentioned study conducted by Mawadza (2004) in Zimbabwe revealed that the shame of having a disease that is strongly associated with sex generates the stigma. In this connection, PLWHA face stigma and discrimination in many areas of their lives mainly because of their HIV status. Supporting Mawadza's findings is Iwuagwu's article (2003), on Challenges of Stigma and Discrimination to Voluntary Counseling and Testing. According to Iwuagwu, stigma which comes from targeting marginalised groups breeds fear and intolerance of these groups in the public. This in turn defines their vulnerability and their ability to protect themselves from HIV or deal with its impact.

Purpose of the Research

As is the case elsewhere in Africa, in Botswana HIV-positive individuals, their families, nurses and other caregivers are confronted with stigma attached to HIV/AIDS. The purpose of this research was to investigate various descriptions used in Botswana to refer to PLWHA and to determine the implications of such descriptions for the dignity of PLWHA. The focus of this paper is on the infected. To achieve this goal the research was guided by the following specific questions:

1. What are the common phrases that people use to describe PLWHA?
2. What are the implications of HIV/AIDS-related descriptions for the dignity of PLWHA?

METHODOLOGY

A descriptive qualitative research design was used to explore the experiences of HIV/AIDS-related stigma experienced by PLWHA in Botswana. Purposive voluntary sampling was used to select participants. This method was found relevant for this study because it enabled the sampled Key Informants (10) to encourage other HIV positive people to voluntarily participate in the study. Further, participation to focus group discussions (FGD) was unrestricted. The sample consisted of 137 participants (37 were HIV-positive and taking ARVs) from Gaborone and four small villages in the southern district of Botswana. These participants between 20 and 60 years of

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age were both primary and secondary school teachers, university students, university staff (both academic and support staff), domestic servants, customary court clerks, farmers and farm labourers, shop and bar assistants and office cleaners.

Data for this study were collected through focus group discussions (FGD), key informants interviews (KII) and informal discussions. FGD and informal discussions were held with members of the communities and KII were held with people living with HIV/AIDS. Informal discussions were held at public places and occasions such as bus queues, food cafes, shops, street talks and various drinking places. FGD were confined to drinking places. KII were held at participants' residences, where they felt less intimidated. All interviews and discussions were conducted in Setswana because all respondents could easily express themselves in Setswana. All KII and FGD were recorded and transcribed. After identifying themes which emerged from the interviews and discussions, data were coded into various categories of HIV/AIDS descriptions. After coding, semantic relationships and patterns were established.

RESULTS AND DISCUSSION

According to Uys et al (2005), there are three types of stigma; external, internal, and secondary. This paper focuses on external stigma. The research first sought to establish common phrases used to describe PLWHA. Having gathered these descriptions, the research proceeded to elicit information pertaining to the implications of such descriptions for the dignity of PLWHA.

Common descriptions

The focus of this paper is on those descriptions specifically directed to the infected. A total of 150 common descriptions used to describe HIV/AIDS or PLWHA were obtained. The informants explained that the descriptions are used in general daily talk or during gossip. Data comprised unique words and expressions, which fall under the following five broad categories, with only the common descriptions cited.

i) Matter-of-fact Statements

It emerged from the results of this research that some descriptions are mere facts about the HIV/AIDS illness and the people who have it. *AIDS*, *mogare* "the virus" and *bolwetsi jwa mogare* "the illness of the virus" is how the illness is generally referred to and these descriptions were common in all the five areas. However, while these expressions appear not to be denoting any harmful allusion, it emerged during the interviews and discussions that these descriptions are generally uttered detrimentally. For example, it was explained that:

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When people see someone passing, they may talk about you, saying that you have AIDS and you are taking the ARVs, just to scorn you. They would be laughing about your situation. If you look at them, they end their conversation and look away or down, as if they have not been laughing about you. When you greet them, they look as if they sympathise with you. But deep down in your heart you know they were laughing about your situation. [An extract from a FGD in a small village in the Ngwaketse area]

This similar concern was expressed in Gaborone:

Unlike other diseases common in Botswana, HIV/AIDS is called mogare or bolwetsi ja mogare. Once you are infected, the whole village starts referring to you as the one suffering from bolwetsi jwa mogare. But they do not say it like in other diseases like high blood pressure, etc. When they say it, they make faces as if you smell. They also talk behind your back as if you have committed a crime. They make you feel very bad and you want to walk fast and go away to be alone. [An extract from a FGD in Gaborone]

It also emerged that some Batswana refer to HIV/AIDS as *bolwetsi jwa 'ilhaka tse nne* “the disease with four letters”. The explanation was that, “*The illness is called AIDS, and it has four letters*”. As is the case with the above descriptions, this label, it was argued, is used in a derogative way. In other words, it is meant to ridicule PLWHA. This description was only uttered in 2 of the four small villages; participants in Gaborone gave no reference to this description.

ii) Appearance Descriptions

Phrases such as, *selo se se sesane* “thin thing”, *lotlhokwa* “stick”, *logong* “log”, *segwapa* “bilton”, *longangale* “dry melon” and *lekwati* “bark” were the most common descriptions of the physical appearance of PLWHA to refer to loss of weight and loss of bodily fluids. These were equally expressed in all the 5 areas. It was explained that, “*When you get AIDS, you become thin and lack nutrients and become weak and look dry*”. The point to emphasise here is that while all the above descriptions signify the physical appearance of the HIV infected individual, there are obviously other people of the same appearance in the community, who are not in a way discriminated. For example one lady said:

You, know, to be honest with you, when I look at myself I always feel and know that there are people who have lost weight more than myself in Gaborone. But to hear people calling me lotlhokwa makes me wonder if I am the only thin person around. But I know that it is because they know that I am HIV positive. [A 35-year-old HIV positive woman from Gaborone]

It also emerged during FGD that:

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People generally refer to them as digwapa, logangale or makwati, anything which is dry because HIV/AIDS drains all the immune system from the patient and one remains dry, weak and unattractive. No, other diseases are different; you do not become that thin and dry. [An extract from a FGD in Gaborone]

Another lady expressed a similar concern:

You cannot call a living person longangale, as if you can eat the person like you do with longangale. You know what, we all know logangale, but when they use these words to describe us they do not use them well. They use them differently; they really want the meaning to be negative. They want us to know that we are shapeless, ugly and dead!! But we are not the only people who are thin in the community. [A 25-year-old HIV positive woman from a small village in Morolong]

It is clear that since in many cases HIV-positive individuals lose weight; their physical appearance is used to describe them. As expected, most respondents confirmed that in most cases loss of weight is associated with HIV/AIDS. However, it is also emerged from these findings that it is not always the case that HIV-positive individuals lose weight. In this connection it was argued that “*the lucky ones do not lose weight and cannot be identified. In this way, they are not discriminated*”.

iii) Denigrating Statements

In general, demeaning descriptions were the ones referring to one's physical condition or social significance. The most common demeaning descriptions cited by almost all participants were *molora* “ashes”, *motlhwa* “something which has been destroyed by termites” and *lekgasa* “*tattered/worn out garment*” to explain the attribution of the uselessness to the individual. The other common description was *sekgoropa/sekorokoro* “*smog*” (emitting worn out vehicle). Since one's immune system has been affected by the virus, he/she is the same as a car which smokes due to the wear and tear condition of some parts which need replacement. The following were some of the common statements during most FGD:

It is common to hear people saying, “Owaii, that one is a real smoker like sekorokoro, his days are numbered”. You cannot disagree when you see the person they are talking about. Some of these people are really struggling a lot [An extract from a FGD in Gaborone].

Have you seen an old cloth having been attacked by motlhwa “termites”? This is exactly how one looks, finished!! Referring to PLWHA as motlhwa describes their undesirable state! Most of them are just moving but finished. So something that has been

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destroyed by mothwa suits their social status [An extract from a FGD from a small village in Gangwaketse].

iv) Death Statements

Most descriptions in this category highlighted that HIV/AIDS is incurable. The most common description was *phamo-kate* “grab and burry”. It was explained that:

“HIV/AIDS is an incurable disease, and when you have it you are sure to die. The disease comes into your body and it grabs you; you die and you are buried”. It also emerged that some people in the villages refer to PLWHA as *kgomo ke yone*, as illustrated by this verbatim statement:

People refer to us as “*kgomo ke yone*”, meaning that HIV/AIDS brands one for life. Once you are infected, there is no escape, you are there for life. This is because even if you take ARVs, it does not mean you will one day escape. You are there for life. This being the case, HIV/AIDS is a permanent brand!! [A 40-year-old HIV positive woman from a small village in Morolong]

v) Commonness of the Illness

The most common description under this category was *bolwetsi jwa diradio* “the radio illness,” indicating how common HIV/AIDS is in Botswana. The other common descriptions were *bolwetsi jo* “this disease” and *bolwetsi jono jo* “this particular illness”. These two phrases describe the common nature of the illness. Another common label used was *bolwetsi jwa bana ba rona* “the illness which is common among our children”, thus signaling its presumed demographic association with the youth.

As was found in the studies by Uys (2005) and Mawadza ((2004), it is also evident from the findings of this research that speaking ill of PLWHA is one of the most common manifestations of stigma in Botswana. It also seems that talking, gossiping, whispering and pointing fingers are all forms of stigma. This paper argues that there is need to desist from this practice as it contradicts Botswana’s Vision 2016; Botswana should be a more compassionate, caring and loving nation.

Implications of HIV/AIDS-related descriptions for the dignity of PLWHA. At this point of our discussion, one wonders whether or not the above explored descriptions have any impact on the dignity of PLWHA. It was important for the central argument of this paper to investigate and establish this issue. In the first place, participants of FGD explored possible emotions and reactions of PLWHA towards various phrases used to describe them. It was explained that *PLWHA* feel bad and rejected, “*some of them run and hide themselves in their houses and can only go out at night when people are not around*”. The most significant finding of this study is that during FGD, participants started to sympathise and empathise with PLWHA, as illustrated by this verbatim statement:

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I wouldn't be happy if I were them. No, this is not fair, it is not their fault. Hei, they hate us, I would if I were them..... You are the first person to ask us questions which make us realise that we are not being fair to others. We have to stop this bad attitude before its too late..... [An extract from a FGD in Gaborone].

It is clear that even though it is common to use various phrases to describe PLWHA, majority of participants realised that such a practice has far reaching consequences for PLWHA. Perhaps it could be argued that stigmatising PLWHA is done without considering its implications for PLWHA.

Having established FGD participants' views on HIV/AIDS-related stigma, the second questions sought the opinions of PLWHA regarding phrases used to describe them. In other words, they were asked how they feel when they hear such descriptions. The point to emphasise here is that the above highlighted concerns were not only expressed during FGD, but also articulated by PLWHA. In general, PLWHA stated that whenever they hear or suspect that people are using negative descriptions to refer to them, they feel "useless", "rejected", "hurt", "isolated", "sad" and "excluded". It is clear that stigmatising PLWHA leads to loss of social identity and self-esteem. For example, HIV/AIDS-related stigma is capable of forcing an infected person to withdraw from family and community members. One lady expressed her feelings this way:

You feel alone and useless. I used to hide in the house and wish I was dead. There was a time when I could not even walk in the village during the day, knowing that people are watching me through their windows and calling me names. Yes, it is very difficult to live among people who blame you because you are HIV-positive. In most cases this is because many people in this village do not understand what HIV/AIDS is all about. The government has to work hard to educate Batswana on HIV/AIDS [A 40-year-old HIV- positive woman from a small village in Gangwaketse].

An encouraging result of this study is that accepting one's status somehow enhances one's self-esteem and self assertiveness, as illustrated by this verbatim statement:

You first have to accept yourself, and then tell your family. Once your family accepts you, you cannot care about people who do not even know their status. When I first discovered that I am HIV-positive, I ran away to stay with my relatives in Gangwaketse. They brought me back when I could not walk. My mother took me to the hospital and I was hospitalised for two weeks..... Oh, these days I don't care; they can continue calling me whatever they like!! [A 35-year-old HIV positive woman from a small village in Morolong]

Since being accepted by the family helps PLWHA to survive HIV/AIDS-related stigma, it is imperative for relatives and friends of PLWHA to accept their infected acquaintances. This is because one's family and friends have a significant role to play in one's life in comparison to distant relatives and community members. However, a worrisome issue that needs to be addressed immediately is the observation that it appears there are still people in Botswana *'who do not understand what HIV/AIDS is all about'*, as pronounced by a majority of participants who are HIV positive. Therefore there is need to strengthen national programmes aimed at educating the nation on issues of HIV/AIDS.

Based on information gathered through KII, it is clear that moral judgment of PLWHA causes stigmatisation. It also seems that PLWHA are often blamed for living with the virus. For example, since transmission of the HIV virus is associated with sexual practices such as promiscuity, homosexuality and prostitution in most communities of Botswana, it is generally felt that PLWHA deserve to suffer. It is on the basis of this misconception that people understand HIV/AIDS in terms of blame. As previously observed, fear is another factor that challenges personal and moral development. In this connection, since HIV/AIDS is associated with immoral practice, PLWHA are usually affected psychologically and spiritually. Consequently, HIV/AIDS-related stigma and discrimination can be as destructive as the epidemic itself.

Based on the above results, this paper argues that not only does stigmatising PLWHA contradict the spirit of loving and caring, it also challenges the dignity of PLWHA. Further, since PLWHA do not freely interact with other members of the community, this paper argues that HIV/AIDS-related stigma denies PLWHA an opportunity to fully develop as individuals. Lack of knowledge, skills and competencies further challenges the dignity of PLWHA as they are likely to feel incapacitated by both the illness and their ignorance.

Implications of the Study for the teaching of Religious Education

It is evident from the above results that HIV/AIDS-related stigma increases the isolation, depression and desperation of PLWHA. Even though this research was not specifically conducted on the role of education in the promotion of tolerance and caring, the results point to the importance of inculcating such attitudes amongst Botswana. The education system has a key role to play in this respect. For example, Mmolai (2007) maintains that, it is through education that Botswana youth can acquire desirable and worthwhile attitudes geared towards the realisation of Vision 2016. This is because subjects such as Religious Education (RE), which lay emphasis on knowledge, skills and attitudes geared towards the promotion of tolerant, compassionate and caring attitudes amongst learners, can have a significant role to play in this regard. This being the case, RE educators should emphasise such attitudes among learners.

Looked at in another way, there is need for PLWHA to accept themselves and prevailing circumstances. For example, we gather from the findings of this study that PLWHA experience enormous strain as a result of social isolation and exclusion due to stigma attached to HIV/AIDS. In particular, RE as a discipline is concerned with personal development, which in most cases helps learners to accept and appreciate their uniqueness and incapability on the one hand, and achieve their potential on the other hand (Mmolai 2008; Mfuni 2007; Dinku, 2002). Hence, it can be argued that RE does not only promote personal development, but it also has a significant role to play in the realization of the four Ds (Democracy, Development, Discipline and Dignity) in Botswana.

SUMMARY AND CONCLUSION

The paper has explored phrases used to describe PLWHA in Botswana. This paper has shown that most descriptions negatively affect the dignity of PLWHA. Despite awareness of the prevalence of HIV/AIDS-related stigma in Botswana, there seems to be minimal effort in strengthening national education programmes on HIV/AIDS, with emphasis on respect for PLWHA. It is therefore crucial that all sectors educate Botswana on the principle of dignity, as emphasised by the President of Botswana in his inaugural speech; especially to ensure its reflection in patterns of language use. But looking beyond the results of this study, HIV/AIDS-related stigma not only denies PLWHA basic human rights to dignity, but also challenges discipline, democracy, development and Botho among Botswana. The major conclusion of this paper is that there is an urgent need for educators in Botswana to emphasise tolerant, compassionate and caring attitudes among learners. Thus, a caring, compassionate and tolerant nation is capable of accepting PLWHA. This will in turn enhance the realisation of the four Ds and Botho in Botswana. Further research is required to address certain unanswered issues. For example the impact of HIV/AIDS-related stigma on family members of HIV-positive people. It is also vital to conduct studies on how best to address HIV/AIDS-related stigma in Botswana.

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