

**The experiences of people living with HIV/AIDS  
in Gaborone, Botswana.**

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in fulfillment of the requirements for the degree of Master of Family Medicine by coursework and research report.

DECLARATION

I, Dr. Vincent Setlhare declare that this research report is my own work. It is being submitted for the degree of Master of Family Medicine in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

..... (Signature of candidate)

..... day of ..... (month), 200...

## DEDICATION

This work is dedicated to my wife who saw to it that I did my work. Without her “encouragement”, this report may not have been written. This work is also dedicated to my parents. Though they were poor working class folk in the townships, all I am, I owe it to them.

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## ABSTRACT

### **Study Aim and Objectives:**

The aim of the study was to explore what it means to have HIV/AIDS in Gaborone, Botswana. The study describes the demographic and socio-economic circumstances of the participants. It also elicits and explores the experiences of people living with HIV/AIDS in Gaborone, Botswana.

### **Methods**

Interviewees were purposely selected from a hospice, an NGO and a church that ministers to PLWHA. In depth interviews were conducted and recorded by audiotape. The interviews were conducted in Setswana and the interviewees responded to a statement, which essentially was, "Tell me about your life since you knew you had HIV/AIDS". The audio recordings were transcribed into English. Care was taken to carry the Setswana way of speaking directly into English. A thematic analysis of the transcripts was made. A modified cut and paste method was used to gather the information into its various themes.

### **Results**

There were 15 interviewees. Their average age was 35.3 years and on average, they had 1.6 children each. They were unemployed.

The interviewees described a wide range of experiences, which were not necessarily experienced by all.

Their narratives described the physical symptoms they suffered. They described stigma and discrimination that they went through. They gave accounts of psychological and emotional turmoil. Psychiatric problems were cited. They were very concerned that they could no longer support their children. They also worried about what would happen to their children when they died.

As their disease progressed, they lost their jobs and were reduced to poverty. They could no longer support themselves and their dependents. They depended on relatives, friends, NGOs and government for relief. Relief from friends and relatives was often not available. They suffered hunger, as they could not satisfy their increased appetites after they started ARV drug therapy.

Their relationships were disrupted when they got ill. Spouses and friends left and some relatives and friends stigmatised them.

Interviewees were taken care of by relatives, friends, health professionals, NGOs, and social workers. In all these categories, there were good and bad care givers except the hospice and church, which were reported as good caregivers. Caregiver fatigue was described.

Some interviewees found comfort in God. They believed that He knows what they are going through and will take care of them. The interviewees also found comfort and healing from the companionship of other PLWHA.

The interviewees wanted to find jobs and work so that they could support themselves and their dependents. They wished government would train them and find them jobs.

### **Conclusion**

The study confirmed the psycho-emotional problems and concern for children felt by PLWHA, that the literature revealed. It showed the physical problems they also suffer. The study revealed that interviewees lost jobs and became destitute. They could not satisfy their increased appetites after they started ARV drug therapy. Interviewees' relationships were disrupted when they got ill. Spouses and friends left and some relatives did not treat them well. There were good and bad care givers in different categories. The African custom of botho/ubuntu seems to be succumbing to the onslaught of HIV/AIDS.

The study showed that interviewees found comfort and support from family, friends, NGO's and the church. They found God and other PLWHA especially valuable support systems.

It was encouraging to notice that some interviewees felt that with time, stigmatisation of PLWHA is gradually subsiding.

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## **CHAPTER 1: INTRODUCTION**

In 1995, Michael et al<sup>1</sup> wrote that HIV/AIDS was probably the most important item on the health agenda at that time. According to them, it was the leading cause of death in adults under the age of forty-five and in children below five years of age. This is the picture in Southern Africa, including Botswana, today.

There are 40,3 million PLWHA world wide, according to UNAIDS/WHO AIDS epidemic update 2005<sup>2</sup>. The same report says that these numbers are increasing in all regions of the world except the Caribbean. The sad fact is that, although only 10% of the world's population live in sub-Saharan Africa, 60% of PLWHA are found in this region<sup>2</sup>. The same source reveals that the epidemic does not seem to be declining in this region except in Zimbabwe. Data gathered from Botswana seems to indicate that the prevalence rate is coming down in Botswana<sup>3</sup>

Southern Africa is home to 2% of the global population but it carries most of the HIV burden of the world according to Halperin and Epstein<sup>4</sup>. They argue that promiscuity in this region is the same as in other less affected regions. They also argue that circumcision rates in men cannot be a factor because other regions with low male circumcision rates have not suffered as much. They posit that it is the habit of having more than one sexual partner concurrently that makes Southern Africa to be so afflicted. The participant in one sexual circle connects to other circles so that a network of interconnecting sexual groups is created. It is then easy for one or a few individuals in the highly infective stage of the disease to affect hundreds of others.

Problems have been cited about AIDS statistical data from Southern Africa<sup>2</sup>. This data is gathered from women attending ante natal clinics, and is therefore from women of reproductive capability who engage in unprotected sex. This excludes males and other females. Data from household surveys have high non-response and absence rates<sup>2</sup>. Despite these problems, necessary modifications of data gathered in this manner enable us to accept the data as the best estimate of the epidemic that we have. The data indicate that there are millions of PLWHA in sub Saharan Africa.

Botswana is a relatively small country in southern Africa. It has a population of about 1.7 million<sup>3</sup>. The Department of HIV/AIDS Prevention and Care, reports that HIV/AIDS was first recognised in Botswana in 1985<sup>3</sup>. It also informs us that, today, 33.5% of pregnant women in Botswana are HIV positive. According to the official government newspaper, Daily News, 68,440 people were on the government sponsored antiretroviral (ARV) drug treatment programme and 11.2% of those eligible for treatment had yet to be enrolled in the programme<sup>5</sup>. Today the number of PLWHA in Botswana far exceeds the 285,000 UNAIDS estimate of 2002<sup>3</sup>. This is because there has not been a significant reduction in infection rates and less people are dying of AIDS because of the government ARV treatment programme. These projections were made before the government had adopted a policy of free ARV treatment for citizens of Botswana.

Thus there are many people in Botswana living with HIV/AIDS. We need to know how these people live, how they take their medicines, how they view programmes that are meant to help them, what they think could be improved or discarded in the fight against HIV/AIDS and a host of other things pertaining to HIV/AIDS. This knowledge would not only inform HIV/AIDS projects, it would also make for recipient friendly programmes that would realize better value for money spent.

Bolton and Milk report that not much research has been done on how affected communities themselves perceive the impact of the HIV epidemic<sup>6</sup>. The same authors point to the need for more research on how local people perceive the impact of HIV/AIDS on their lives. This is crucial for the planning and implementation of appropriate health and social care<sup>7</sup>. However well intentioned programmes are, they need a backbone of research. Research provides data that forms the basis for good decisions. When such data is lacking, mistakes may be made. Unfortunately HIV/AIDS is unforgiving and every error in the fight against it is punished by more infection, more transmission, more disease and more deaths.

The purpose of this study was to find out how people living with HIV/AIDS (PLWHA) live their day-to-day lives. This was done by listening to the PLWHA relate their experiences.

## **CHAPTER 2: LITERATURE REVIEW**

In Botswana some research has been done on the various aspects of HIV/AIDS but a lot still needs to be done. A reporter for a local newspaper, quotes Professor Torto, a professor of analytical chemistry at the University of Botswana as saying, in connection with AIDS research, "... to the best of my knowledge, as scientists at the University of Botswana, we are watching from the sidelines.....as it was clearly stated (at the Johannesburg World Summit), a nation with a problem should lead in finding its solution<sup>8</sup>."

There is a substantial body of knowledge that research has brought to light with respect to PLWHA. This knowledge includes issues pertaining to stigma and discrimination, poverty and joblessness, emotional and psychological issues, caregiver and relationship issues' and a host of other data.

### **Stigma**

Stigma has been described as that quality that significantly discredits an individual in the eyes of others<sup>9</sup>. Posel writes that it is a visible mark borne by an individual, which is negatively valued by the group of which the individual is a member<sup>10</sup>. In connection with AIDS, she elaborates how bodily decay and seepage of faeces, blood and pus from an AIDS patient would naturally elicit strong reactions<sup>10</sup>. These reactions include disgust on the part of those who do not have AIDS to shame on the part of those who have it, she writes. Thus stigma sets AIDS apart from other terminal diseases and is defined as a mark of shame or discredit<sup>11</sup>.

Anderson and Doyal<sup>7</sup>, in their study of African women living with HIV in London, showed that HIV/AIDS is a very stigmatising condition. As the study showed, this stigma could be due to the negative and socially unacceptable behaviour that has been associated with HIV/AIDS, like prostitution and promiscuity. Homosexuality and drug use are some of the other negative social behaviours that have been associated with the condition according to the UNAIDS report on stigma and discrimination<sup>2</sup>. Knox, Davis and Friedrich have also connected the stigma of HIV/AIDS to the fact that in the beginning, HIV/AIDS was disproportionately seen in stigmatised groups<sup>1</sup>.

Stigma leads to discrimination against PLWHA and according to the same UNAIDS report, this is happening in all regions and in all countries. UNAIDS reports that this discrimination is seen in hospitals, schools, the workplace, and that even the right to marry may be denied PLWHA. Boer and Emons report that stigmatising reactions include a perception of higher risk from casual contact<sup>12</sup>. Thus shaking hands or hugging PLWHA may be deemed to expose one to infection with HIV. They report that PLWHA are blamed for their condition and there is increased support for policies to restrict their freedom. Anderson and Doyal found that HIV positive women are rejected by their husbands or partners, evicted from their homes, refused contact with children, and the utensils they use are marked or given special washing. Letamo's study in Botswana also showed the existence of the belief that one can get HIV/AIDS from sharing a meal with PLWHA<sup>13</sup>.

Kgakole found that in Botswana, stigma is present in health facilities, families, and communities<sup>14</sup>. His study shows that PLWHA are isolated in their own families and at social functions. Kgakole's work also showed that women are disproportionately blamed for HIV/AIDS and that their partners and families also reject them. In their study in India, on the coping patterns of seropositive wives of men with HIV/AIDS, Joseph and Bhatti found that the women were blamed for infecting their husbands, they suffered intramarital communication breakdown, they had difficulty in maintaining their social network, and a host of other problems due to stigma and discrimination<sup>15</sup>.

### **Psychiatric, psychological and emotional issues**

It is therefore not surprising that PLWHA have psychological, emotional and psychiatric problems<sup>16,7,17</sup>. Among other things, these studies show that PLWHA suffer intolerable levels of self blame, difficulty in remembering or concentrating, high levels of psychological distress, psycho-neurological symptoms and depression. This kind of suffering is best expressed by PLWHA themselves. One man discovered that he had HIV/AIDS after his wife and son had died of the disease<sup>18</sup>. This man's wife had never disclosed to him and he claims he was a faithful husband. This is what the man said about his situation. "I am in great pain. My heart aches terribly. My wife betrayed me. While I was struggling for the family, she was cheating on me", he said. Ngele, one of the best known HIV/AIDS activists in Botswana says that at one stage in his life, he perceived HIV/AIDS to be a death sentence and decided that he was going to end his life<sup>19</sup>. Frank, Bhindo and Brabant found that women have to deal with the problems of dying and leaving their children, of having infected their children and intolerable levels of self-blame<sup>17</sup>. Joseph and Bhatti, in their study in India, report that women had strong feelings of guilt and concern for their innocently infected children and that they questioned the justice of the "Supreme Being"<sup>15</sup>. Busang and Tharakan found that 43% of patients in their study had sleep loss while 91% reported that they had depression<sup>20</sup>.

One may be led to think that this psycho-emotional trauma that PLWHA suffer is due to their lack of knowledge about the disease. Studies show that even health professionals have the same problems when they suffer high risk exposure to HIV/AIDS such as needle pricks or contact with infectious body fluids. Newton found that shock, disbelief, and a feeling "like being hit on the head with a hammer" are the initial reactions to high risk occupational exposure, in nurses<sup>21</sup>. This was later followed by fear, anger and the nurses felt that being HIV positive equals death. She found that when nurses had been so exposed, they developed an altered self image. It was as if they became a new person, the HIV positive person.

### **Unemployment**

Another problem that PLWHA suffer is unemployment. In a study in France, Dray-Spira et al found that only about 50% of PLWHA were employed<sup>22</sup>. They found that 10% of their respondents experienced work related discrimination like dismissal, threat of dismissal, non renewal of contract, and being isolated and kept in the background. Mast et al found

that HIV infected women find it difficult to work<sup>23</sup>. They found that even minor jobs are difficult for them when they are ill. Reporting from Botswana, Kalane states that when PLWHA became sick or disclosed their status, they lost their jobs and their financial freedom<sup>24</sup>. Busang and Tharakan<sup>20</sup>, in the study cited above found that 49% cent of the patients were unemployed and that 50% of them earned three hundred pula or less, per month. Joseph and Bhatti in their study in India, of seropositive wives of men who had HIV/AIDS, found that these women experienced financial difficulties after diagnosis of HIV/AIDS in their families<sup>15</sup>. This was because of loss of jobs by their husbands or themselves. Bolton and Milk in their study in Uganda, on how Africans view the impact of HIV, reported that their respondents listed poverty, reduced income and lack of food as the main problems<sup>6</sup>. This is most probably because of loss of employment and inability to work. In Botswana, "a large coalition of organisations and individuals have launched a campaign urging the Botswana government and policy makers to put in place a law to protect HIV related rights in the workplace"<sup>25</sup>

### **Food and nutrition**

Food is a very important item in the fight against HIV/AIDS. Lack of food may lead to early deaths in women who have AIDS as Frank, Bhindo and Brabant<sup>17</sup> state in their published study in HIV infected women in Louisiana, USA. Brown and Boag state that observational studies have demonstrated that micronutrient deficiencies in HIV positive individuals are associated with faster disease progression and mortality<sup>26</sup>. Fawzi, Msamanga et al, in a study (in HIV infected women) on pregnancy outcomes in Tanzania, found that multivitamin supplements given in pregnancy led to significant increase in CD<sub>4</sub>, CD<sub>8</sub>, and CD<sub>3</sub> counts and reduced infant mortality<sup>27</sup>. Andrews suggests that nutrition remains a cornerstone of HIV management and advises that nutritional intervention and dietary recommendations should be started early<sup>28</sup>. He recommends a diet with enough energy, protein, and vitamins, that is well balanced. Unfortunately this kind of diet is a pipe dream for poor, out of work PLWHA. In recognition of the situation of AIDS patients and the need for a balanced diet, the government of Botswana put in place a programme of giving free rations to such patients. The AIDS community was shocked recently when the government downsized this programme<sup>29</sup>. Of all the programmes to cut, this should have been last on the list because, as government has correctly assessed, the fight against HIV/AIDS is a fight for the survival of Botswana as a nation.

### **Poverty**

Poverty and reduced income is indeed one of the major outcomes of HIV/AIDS in a community<sup>6</sup>, and when PLWHA got sick or disclosed their status, they lost their jobs and their financial freedom<sup>24</sup>. PLWHA desire to extricate themselves from poverty. Bolton and Milk found that 81.3% of patients in their study needed financial assistance and that 62.5% of them needed employment<sup>6</sup>. Anderson and Doyal found that most African women living with HIV in London, disliked taking benefits and preferred to work and support themselves<sup>19</sup>. One of the interesting things that came to light in Anderson and Doyal's study was that most women felt that finding "something to do" (work or study) was the most important thing

that would improve their lives. Finding jobs is made difficult for PLWHA because as mentioned above they are discriminated against.

Poverty among PLWHA results in poor accommodation. These people have no housing, are about to lose their housing, or require a different type of housing as shown by Stajduhar and Lindsey<sup>30</sup>. They found that PLWHA prefer to be cared for at home and that they do not like institutional care.

## **Relationships**

PLWHA also have to contend with interpersonal relationships and living in a community. Joseph and Bhatti, in their study in India, found that there were problems in sexual interaction and sexual intimacy after diagnosis of HIV<sup>15</sup>. They also reported that most respondents noticed a change for the worse in their marital relationship after HIV diagnosis. The same Indian study also showed that the seropositive women had self imposed restrictions in social interactions because of shame, fear of stigma and because they no longer thought that they were attractive. Joseph and Bhatti also found that relations in the social circles and families of respondents became strained as a result of a HIV diagnosis.

Ingersoll reports that PLWHA develop social phobia<sup>31</sup>. They have persistent fear of interpersonal situations or scrutiny by others and avoid such situations. Anderson and Doyal's study showed that women had great anxiety about being known to be HIV positive, being seen at the clinic and their medicines being seen<sup>7</sup>. Thus this need for secrecy was a great constraint on these women's lives. Anderson and Doyal also mention that they found these women were rejected by their husbands or partners, because they were HIV positive. They are rejected and isolated according to the Frank, Bhindo, and Brabant study which is quoted above<sup>17</sup>. Kgakole, in his work in Botswana<sup>14</sup>, also mentions that PLWHA are isolated in their families and at social functions.

## **Adherence to treatment**

Adherence to drug treatment is of paramount importance in the lives of PLWHA. Without adherence, they become ill and may die. Lack of adherence also has a bearing on the management of the AIDS epidemic because it makes it easier for resistant strains of HIV to emerge. Heckman et al found that increased alcohol use had a negative effect on adherence while a good relationship with the attending physician had a positive effect<sup>32</sup>. Ingersoll's study showed that use of crack cocaine in the past six months, history of ever using heroin and any other substance abuse were negatively associated with adherence<sup>31</sup>.

## **Spirituality**

“Whether or not a human service worker finds meaning in an organised religious group or from personal spiritual reflection, many professional's case loads will include persons who find meaning in such things. Religion and spiritual issues can influence an individual's basic coping mechanisms, orientation to life and death, and definition of self”<sup>33</sup>. It is therefore not surprising that people suffering from a devastating disease



such as HIV/AIDS use spirituality and religious groups as part of their coping armament. Heath and Rodway in their study in Canada in women who had HIV infection, found a deepening of spiritual beliefs experienced by some of the women<sup>11</sup>. Some people, immediately after diagnosis, have to deal with spiritual and existential issues because of the link between AIDS and untimely death<sup>34</sup>. Somlai et al found that after diagnosis, HIV positive women invested in spiritual coping strategies and that they believed that divine intercession had renewed their spiritual growth and connectedness with others<sup>35</sup>. In India, Joseph and Bhatti found that seropositive women spent an increased amount of time in religious activities, after their HIV diagnosis<sup>15</sup>.

This shows that spirituality and religion are an important element, in the lives of some PLWHA.

### **Companionship of other PLWHA**

People with HIV/AIDS like the companionship of other PLWHA. Heath and Rodway found that most of the women in their study wished to meet with other HIV positive women<sup>11</sup>. This is because they seek social support to express their emotions and concerns<sup>36</sup>. This is generally not forthcoming from their communities. They are stigmatised and isolated as has been shown above. PLWHA would gravitate to the companionship of similarly infected people because they support and understand one another. Heath and Rodway found that HIV positive women seek, “a good listener, non judgemental respect, and emotional as well as practical support”<sup>11</sup>.

### **Social phobia, isolation, and reclusiveness**

The diagnosis of HIV disrupts the normal pattern of living, according to the findings of Joseph and Bhatti in India<sup>15</sup>.

PLWHA at one time or another have reduced social contact. This is mainly due to the stigma of HIV/AIDS. This forces them to keep their affliction a closely guarded secret, by keeping to themselves. The shame which they feel, also makes them want to isolate themselves from a public that is disgusted by their condition as Posel has indicated<sup>10</sup>. Joseph and Bhatti also found this tendency to self-isolate, in seropositive women, because of shame, stigma and the feeling that they were no longer attractive<sup>15</sup>.

Thus we see that when a person becomes HIV positive, they encounter a number of new life experiences. These experiences are peculiar to the status of being HIV positive because this condition is unique. There has never been a disease or condition like HIV/AIDS in the history of mankind. Although there are and have been many deadly diseases in the past, HIV/AIDS has pathological, social, emotional and psychological characteristics that make it outstandingly unique.

### **Similar Studies**

Two studies that are similar to this study were done in India and in Canada.

In India, Joseph and Bhatti<sup>15</sup> studied the psychosocial problems and coping patterns adopted by seropositive wives of men with HIV/AIDS, post HIV diagnosis. They used an information data sheet to compile demographic and illness variables. They used the semi structured interview method and the modified Coping Scale developed by Lazarus and Folkman to assess psychosocial problems and coping patterns<sup>37</sup>. The mean age of the respondents was 21.57years (range was 18 to 40). Joseph and Bhatti found that these women suffered job loss, and had financial problems. They also found that the women had a lot of concerns and worries about their children. They experienced marital problems, stigma and shame. Joseph and Bhatti found that the women had difficulty maintaining their social networks and that their social interactions diminished post HIV diagnosis. These women were still expected to take care of their sick husband when they themselves were not cared for. The women became more religious but kept more to themselves because of stigma and shame. Joseph and Bhatti report that these women had constant thoughts of death and dying, and that their overriding emotion was fear. The commonly adopted coping mechanism was that of escape avoidance.

In Canada, Heath and Rodway used a questionnaire and individual interviews to study the psychosocial needs of women infected with HIV<sup>11</sup>. The mean age of the interviewees was 34.52 years.

Heath and Rodway found that, at the time of diagnosis, these women needed “someone to listen to my concerns” and “someone to be there with me”. Spirituality emerged as an important factor in the lives of these women. Some of the women were not happy with the care and support they got from health care workers, at the time of diagnosis. All the women reported that they had someone who was giving them help and support- family members, other PLWHA, counsellors and health care workers. Most of the women wished to meet with other women who had HIV infection. Those who had children had fears about their own premature death and what would happen to their children thereafter. They found that stigma was prevalent and that it impacted the women’s self-esteem, power and control.



## **CHAPTER 3: METHODS**

### **Study design**

This was a qualitative study. The study was done in Gaborone between July and September 2006. Interviews were conducted at the rate of one or two interviews per week.

### **Site of study**

The study was conducted in Gaborone.

Gaborone is the capital city of Botswana. It has a population of 186 000 (Botswana 2001 census). The city has a mixed population composed of Africans, Indians, Caucasians, and Chinese. The vast majority are Africans (Botswana and Africans from beyond Botswana's northern borders). The city has a government referral hospital with specialists. It also boasts of a state of the art modern private hospital with specialists and ultra modern equipment. There are many government clinics and many private doctors practicing in the city. The HIV prevalence in pregnant women in Gaborone is 44.8%<sup>38</sup>. The government referral hospital and the private hospital, have AIDS clinics where patients get their anti-retroviral (ARV) drug treatment. Many private doctors also give ARVs to HIV/AIDS patients. People are tested for HIV at Tebelopele (a non governmental organization-NGO), at the government referral hospital, at the private hospital, and all clinics and private doctors have easy access to HIV/AIDS testing facilities throughout Botswana.

The participants in this study were found at Holy Cross Hospice at Bontleng, Matlo Go Sha Mabapi in Old Naledi and the Old Naledi Baptist Church.

The Holy cross Hospice is run by the Anglican Church. It caters for patients who are very ill (usually TB, and or AIDS). The patients are given food, medical attention and other assistance that they may require. The patients are collected from their homes in the mornings and in the afternoon they are taken back to their homes. This is done three days a week. When the patients get better, they are discharged from the hospice. They no longer need to go to the hospice.

Matlo Go Sha Mabapi is a support group for people infected and affected by HIV. It was formed by and is also run by people with HIV/AIDS. This is an organization which caters for people who are infected or are affected by HIV/AIDS. Its members meet regularly to support and encourage each other. The organization also offers counseling to its members. It is an NGO that gets funds from donors and tries to channel these funds to empower its members.

Old Naledi Baptist church has people in its congregation who have HIV/AIDS and the pastor assists these people however he can.

All these organizations are in Gaborone.

## **Study population**

The study population was all PLWHA who were clients of The Holy Cross Hospice, Matlo Go Sha Mabapi and Old Naledi Baptist Church, in Gaborone, Botswana.

## **Sampling**

Non-random sequential sampling was used. This means that interviews with additional patients were conducted until it was felt that no new information or type of interviewee was being added to the research.<sup>39</sup> The researcher continuously reviewed all collected data in order to determine when this point had been reached.

The size of the sample was determined by the number at which data collected reached “saturation point”. This is the point at which the researcher felt that no new information or type of interviewee was being generated from interviews.

The sample consisted of people who gave their free consent to be interviewed; people who also satisfied the inclusion and exclusion criteria. The researcher also used purposive sampling. This means that settings where participants could be easily reached were identified and especially informative participants were selected.<sup>40</sup> Non governmental organizations (NGOs), Home Based Care (HBC) programs, churches with HIV/AIDS programs etc. are examples of such settings.

The Director of the Holy Cross hospice was asked for permission to do this research in her institution. She asked for a copy of the protocol and gave her consent thereafter. She identified a lady who would be the researcher’s contact person. The researcher would contact this lady to tell her when he was going to conduct interviews. The same lady introduced the researcher to her clients and helped him to select suitable interviewees because she knew her clients better. A room was provided for conducting interviews in, but usually it was more convenient to find a secluded space in the hospice grounds. There was a lot of human traffic, hustle and bustle in the busy building.

None of those approached declined and the interviewees seemed to like to share their stories. At the end of the interview, some food was given to the interviewee to take home. This was a token of appreciation of his/her time and also a token of support.

The researcher went to the Old Naledi government clinic to source interviewees. He found out that there would be a lot of red tape and formalities before the interviews could be conducted. This was despite the fact that permission had already been granted at the Ministry of Health headquarters.

The researcher was then directed to Matlo Go Sha Mabapi in Old Naledi. The leader of this group was at first very skeptical about conducting research in her organization. She said that many people (including those

from overseas) had interviewed them but they never got any feedback or benefit from such research. After some discussion, she was convinced that she should allow me to do research in her organization. It was during this discussion that she said something that would stay with me for a long time. She said, "You see most of us PLWHA are dying, not because of the virus, but because of hunger." She was not echoing the infamous words of a president. She was simply stating the fact that HIV/AIDS is more devastating in those who do not have food.

Inclusion criteria:

1. PLWHA living in Gaborone.
2. People with HIV/AIDS, irrespective of the stage of the disease.
3. People who were well enough to answer questions for themselves.
4. People who were 18 years or older.
5. People who gave their consent to participate in the study.

### **Measuring tool or instrument**

Data was collected using the in depth interview method. The researcher had a face-to-face interview with each participant and this was audio taped. The audio interviews were conducted in Setswana. They were later transcribed into English.

The research statement was, "Tell me about your life since you knew that you have HIV/AIDS." This statement was chosen because it is in line with the objectives of the study, which was to learn from PLWHA how they lived their lives, and what their experiences were as they lived their lives. This statement is also acceptable in the setting of the study, which is in Gaborone, Botswana. The researcher felt that a direct question like, "What has your life been like since you knew you had HIV/AIDS?" would sound like an interrogation. It would be impolite. Direct questions like this, about issues considered sensitive in this setting were only used after some rapport had been firmly established.

The statement at times would be repeated, later on in the interview as a question e.g. 1. "How has your life been since you knew you had HIV/AIDS?" 2. "How is your life?" 3. "How are your feelings?" 4. "Tell me how you live with other people in this community". 5. "How do you manage since you became aware that you have HIV/AIDS?" It was from such additional statements and questions that interviewees gave fuller accounts of their stories. Had this not been done, the interviewer would have ended up with very little information about the lives of PLWHA. Part of the reason for this is that talking a lot is regarded to be immodest in this community. "O bua thata or oa balabala" ("He speaks a lot" or "He is always saying something") are unfavourable comments used to describe those who talk a lot or those who are mad. It is also considered indiscrete to talk a lot/at length to strangers, especially about very important things. Thus the first response to a question or enquiry from a stranger may be cursory or immaterial (without substance). It is only after rapport is created that substantive answers can be elicited. This is another reason why the research statement had to be repeated as it was or in different ways, during the interview.

People tend to be reluctant to provide interviewers with information on sensitive issues and resent this invasion on their privacy<sup>41</sup>. Thus the interviewer had to take extra care in being sensitive and considerate of the feelings of interviewees. This was done in part by the interviewer assuming a learning attitude and thus rendering the interviewee the source of valuable information. The interviewer tried at all times to apply the social graces and etiquette expected of him under the circumstances.

The researcher was a complete stranger to all the interviewees. Divulging sensitive information to a stranger elicits feelings of anxiety. Mouton states that one way of alleviating anxiety about divulging information on sensitive issues is to assure interviewees that their responses and identity will remain anonymous<sup>41</sup>. Thus the researcher took time to assure the interviewees that their identities would not be divulged to anyone. The researcher also explained that the interviewees would never be individually identified with any statement that was associated with the report.

The researcher's interview technique was influenced, to a large extent, by the ideas of Denzin and Hugo.

Qualitative researchers generally agree that the in depth interview seeks to, according to Denzin, "actively enter the worlds of people and to render those worlds understandable from the ... behaviours, languages, definitions, attitudes and feelings of those studied."<sup>42</sup> There are various renderings of how this is achieved in the study field. Some would say that "the interviewer asks an open question and then by the use of summarizing techniques and questions of clarification draws out the meaning and sense of reality that the interviewee places on the issues under discussion"<sup>43</sup>. Some suggest that a series of open ended questions can be asked<sup>42</sup>.

In a preparatory workshop for this project, Prof. Jannie Hugo gave a very lucid presentation of his understanding of this subject. He believes that the purpose of the in depth interview in qualitative research is to bring forth the interviewee's understanding of reality on a particular topic. In Prof Hugo's understanding of the in depth interview method, the interviewee is asked a question and is given freedom to answer as he sees fit. The interviewer only says back to the interviewee what he understands him to be saying. The interviewee then affirms or corrects what has been said back to him.

## **Ethics**

The ethics clearance for the research was obtained from the Human Research Ethics Committee (Medical) at the University of the Witwatersrand (HREC) and is attached (cf Appendix 1). Also attached as an appendix is a letter written to the Permanent Secretary, Ministry of Health (Botswana), asking her for permission to conduct the research in Botswana (cf Appendix2). Permission to do the research was given by the Ministry of Health in Botswana (cf Appendix 3).

The Director of The Holy Cross Hospice was asked for permission to conduct research at the hospice. The letter asking for this permission is attached (cf Appendix 4). She gave her consent verbally thereafter.

The leader of Matlo Go Sha Mabapi, and the Pastor of Old Naledi Baptist Church were verbally asked for permission to conduct research in their respective organisations. They both gave their permission verbally.

Interviewees were formally asked to give their consent. It was explained to them that they were free to accept or decline the invitation to be interviewed. The researcher also informed them that all information they were going to give was confidential and that their identity would not be revealed in any way in any report or media. The interviewer then explained the need to audiotape the interview. The contents of the information that was given to interviews before they were asked to participate is attached (cf. Appendix 5).

The respondents were all interviewed in private. All gave their consent to be interviewed. No pressure was applied to get this consent.

All materials- transcripts, tapes and other information pertaining to this study are going to be destroyed as soon as the study report is approved.

### **Pilot study**

A pilot study was done. This involved interviews with A2, A3 and A4. The data from these interviews was included in the main study because it was similar to the data collected from the research study. It added depth to the data in the research study.

The purpose of the pilot study was among other things to find out if the interviewees understood the research statement that was put to them. The researcher also wanted to find out how they understood it. The pilot study, it was hoped, would help the researcher find an acceptable way to put the research statement. This means acceptable in a cultural sense and in as far as soliciting the required response from interviewees. The pilot study was also meant to find out the conditions in the study fields i.e. logistics, "gatekeepers" (people who would facilitate or permit access to interviewees), mutually suitable times for conducting interviews at institutions, and suitable locations for conducting interviews.

The pilot study also helped to familiarize the interviewer with the audio recording equipment. The microphone had to be attached in a certain way, at a suitable distance from the mouth with nothing obstructing the voice on its way to the microphone. The interviewer also had to learn how to assure interviewees that recording their utterances had no sinister motives.

It became clear during the pilot study that the interviewees were not used to giving elaborate discourses about abstract ideas concerning their lives. It seemed they were more familiar with concrete thoughts and thus they would feel they had said everything they needed saying in a few sentences. It was by encouraging them to speak more and by asking them

to elaborate and explain what they meant that valuable information was elicited.

Though the interviewer expected each interview to last about one hour or more, the interviews proved to be much shorter in the pilot study. This was in spite of a lot of effort on the part of the interviewer to keep the interview going.

### **Data collection**

The in depth interview method was used. The interviews were audio-recorded.

The researcher could afford only one free afternoon (free from work) per week to conduct interviews. The hospice, which provided most of the interviewees, had time constraints. They closed down at about 3.30 pm, in order to transport their clients (the interviewees) back to their homes. The hospice also hosted their clients three afternoons a week. Thus the nine hospice participants were interviewed over a period of about six weeks.

The four participants from Matlo Go Sha Mabapi were interviewed in a single afternoon. Their leader arranged a meeting, at her home, for that particular day. The participants were seen individually in the leader's lounge.

The two participants from The Old Naledi Baptist Church were seen on two different days. One participant was interviewed in the researcher's car, in the church compound, because church premises were not open that day. The other was interviewed in the church's office.

The usual cultural formalities were adhered to before gathering data. This consisted of the usual greetings and the assumption of a polite and respectful attitude to the interviewee. The initial remarks and exchanges were to make the interviewee feel respected and honoured as a human being - the ubuntu/botho platform.

Botho or Ubuntu is common decency. It is the amalgam of etiquette, social decorum and practice that promotes harmony and peace in a community. Botho or Ubuntu is founded on the bedrock of respect for people regardless of their status. The understanding that all people are valuable just because they are human beings undergirds it.

The interviewer was also sensitive, at all times, to the fact that gathering such sensitive data is difficult for interviewees and may be construed by them to be an unnecessary intrusion into their privacy.

Then demographic data was collected. A representative type of questions that were used to gather demographic data is attached (cf. Appendix 6). This included age, sex, number of children, whether the interviewee was working or not, where he stayed and if he owned the place he stayed at. They were also asked about their marital status and if they were still together with their spouses.

Marital status was asked as part of the demographic data. It is important to note that in the community in which the study was conducted, common law marriage, that is people of opposite sex staying together as if they are formally (western type) married, when they are not formally married, is common. These liaisons are common, and legally binding before the law. For those interviewees who were not married, the researcher asked if they had lovers/partners. The researcher thought it was important to know about the marital status and love relationships of the interviewees because they affect people's lives. The essence of the enquiry about marital status and love relationships was to add to the demographic profile of the interviewees. This enquiry also helped to explore how HIV/AIDS had affected marriages and relationships. Thus it was important to know if PLWHA had retained their husbands, wives, and lovers/partners after the diagnosis was known.

The final part of the interview consisted of asking the participants to give an account of their lives after they discovered that they had HIV/AIDS. This statement was put to them. "Tell me about your life after you were told that you have HIV/AIDS." Sometimes, variations of this statement would be put to the interviewee as a statement or as a question. However the statement or question was put, it was to enquire about the interviewee's life after they knew that they had HIV/AIDS.

## **Analysis**

The Setswana interviews were transcribed into English. As much as was possible, a literal translation into English was made so as not to lose the mindset, idioms and the cultural paradigm of what was said. This made the English in the transcriptions strange and untidy quite often. It is hoped that the Setswana paradigm was preserved in the process.

It is important at this point to point out the limitations of transcription. Green and Thorogood mention a researcher in Cameroon who ultimately discovered that the overlap between local terms and medical terms was only partial<sup>44</sup>. Thus one can realize that the English transcripts may not have availed all that interviewees had to say.

After reading through the transcribed interviews several times, a few themes emerged. The themes were colour-coded. The utterances of each interviewee were then cut and grouped together according to the colour-coded themes. The colour-coded themes from all interviewees were then grouped together in categories according to these themes. These theme categories were read several times. A summary of each theme category was then made.

Professor A. A. Alao, a professor of sociology at the University of Botswana, was given the uncoded transcripts to look at and he was asked to indicate what, in his view, the themes were. Neither his department nor Professor Alao provided this input, and after two months of waiting, it was felt that writing the report could not be delayed indefinitely. The report was thus written without this input. This input has not been received by the researcher to date.



Member checks, that is taking the transcripts back to the interviewees, to read through them and correct them was not done. Probably only three interviewees would have been able to read a transcript which was written in English. The rest of the interviewees did not know English. Of these three it is likely that only one had a good enough command of English to go through a transcript. Transcribing the manuscripts into Setswana and then into English would have been a monumental task. Asking the interviewees to read and correct the Setswana transcripts is likely to have been a futile exercise. Reading is not a common practice among the type of interviewees one encountered in this study. Reading the Setswana transcript to each interviewee, and then asking for comments and corrections would have taken a very long time.

It is also important to reflect on the necessity of doing member checks of transcripts, that have been transcribed from audiotapes, which bare the exact utterances of interviewees. The audiotapes are listened to over and over during transcription and this is a far better member check and it does not run the risk of editing (interviewees modifying, reviewing, or eliminating what they said, for various reasons). In the absence of audio taped or videotaped material, member checks would be necessary though they run the risk of editing.

### **Limitations**

There was a time and logistical constraint at the Holy Cross hospice. The interviewer usually arrived at the hospice during lunchtime. The hospice clients were having their valuable meal and it was very gracious of them to agree to be interviewed at this time. Immediately after the meal, the hospice transported their clients back to their homes. The interview was conducted with both these facts in mind and one wonders to what extent this affected the interview.

Although all interviewees seemed to understand and answer all questions put to them. HIV/AIDS had affected some of them psychologically, neurologically, mentally, physically, and emotionally as the transcripts show. This may have had a bearing on their cognitive and expressive faculties.

The interviewees from Matlo Go Sha Mabapi, are a cohesive group and they have a strong leader. The leader is to some extent an advocate and activist for the rights of PLWHA. One wonders to what extent the leader, with no intention to do so and without malice, has shaped the views of the members of this group. Since the interviewees were interviewed in private, one hopes that this minimized the leader's effect as much as possible. The interviewer also tried to create rapport with the interviewees. The interviewer met them in their territory and spoke in their language. He was polite, and tried as much as possible to make them feel that they were reservoirs of very valuable information that the interviewer needed. The interview was conducted over a cup of tea and some bread.

Mouton<sup>41</sup> has said that role-playing is minimized if enough rapport exists between the interviewer and interviewee. Thus it is hoped that the



measures mentioned above created enough rapport so that the interviewees did not merely say what they thought was expected of them.

Member checks, that is taking the transcripts back to the interviewees, to read through them and correct them was not done. The reasons for this are discussed in the section on analysis.

The data, results and conclusions of this study refer only to the experiences of the research interviewees. They are not necessarily representative of the experiences of all PLWHA in Gaborone.

## **CHAPTER 4: RESULTS**

A total of fifteen people were interviewed. All the people who were asked to be interviewed agreed to be interviewed.

It became clear during the pilot study that the interviewees were not used to giving elaborate discourses about abstract ideas concerning their lives. It seemed they were more familiar with concrete thoughts and thus they would feel they had said everything they needed saying in a few sentences. It was by encouraging them to speak more and by asking them to elaborate and explain what they meant that valuable information was elicited.

The pilot study showed that one would have to phrase the research statement in several different ways in order to elicit a substantive response from the interviewee.

Sometimes interviewees would want the research statement to be explained because they had difficulty in understanding its essence. The researcher would then explain that he wanted to know how the interviewee lived his day-to-day life, his experiences and that the researcher wanted to know the feelings and thoughts of the interviewee. The researcher and interviewee finally reached a common understanding of what the researcher wanted to know. It was only then, that the interview could proceed smoothly.

At times, especially when talking about sensitive things, Batswana find it easier to talk about them as if they are talking about another person. "A person must respect his uncle." This is one way of saying, "You must respect me I am your uncle." The former is non confrontational and is easier to say. The interviewer found that it was easier for some interviewees to avoid confronting their feelings, thoughts, emotions etc by talking in this manner.

### **Demographic profiles of interviewees**

All the interviewees were living in Gaborone at the time the study was made. They all lived in the high density (poor) townships of this city. All of them had HIV infection and all except two had AIDS. They were all well enough to be engaged in a conversation and all the respondents were adults (i.e. over eighteen years old). Their ages ranged from 28 years to 47 years. The average age was 35.3 years. The demographic details of the interviewees are shown in Table1.

Two interviewees were from the Old Naledi Baptist Church, four were from Matlo Go Sha Mabapi and nine were from the Holy Cross Hospice. There were five males and ten females.

Ten interviewees had children while five did not have any. For the 15 interviewees, each one had, on average, 1.6 children. The 10 interviewees, who had living children, had, on average, 2.4 children each. One of the females who did not have children had lost all of her children in their infancy.

Fourteen respondents were unemployed. Twelve were unemployed because of HIV/AIDS. Of these fourteen, there were some who did piece jobs whenever they could find them and one was occasionally self-employed on a very small scale. One respondent was on a long sick leave (two and a half years) because of HIV/AIDS. This respondent was receiving half of his salary and complained that it was inadequate for his needs.

Most of the respondents depended on other people for their livelihood.

Table 1.

**Demographic profiles of interviewees**

Interviewee	Age	Sex	Children	Employment status	Support system
A1	30	F	2	unemployed due to HIV/AIDS	one working sister; hospice-food and encouragement
A2	38	M	3	unemployed due to HIV/AIDS	one working nephew, rare piece jobs, hospice-food
A3	35	F	2	unemployed due to HIV/AIDS	two working family members, hospice, council- free food
A4	36	M	0	unemployed due to HIV/AIDS	one working aunt, gifts from friends, hospice-food, God
A6	32	F	0*	unemployed due to HIV/AIDS	father's rent income, hospice-food and nursing, God
A7	35	F	2	unemployed due to HIV/AIDS	one working sister, council-free food
A8	28	F	0	unemployed, her job got finished	one working cousin, hospice
A10	30	M	0	unemployed due to HIV/AIDS	aunt's rent income, hospice-clothes
A11	35+	M	1	employed, on half salary due to HIV/AIDS	long sick leave-on half salary
A12	28+	M	0	unemployed, sacked for complaining	works-sometimes, God
A13	37	F	4	unemployed due to HIV/AIDS	lots of counselling, rent from two rooms, piece jobs, council-free food
A14	36	F	3	unemployed due to HIV	father's rent income, self employed, support group
A15	36	F	3	unemployed due to HIV/AIDS	piece jobs, support group, sister does piece jobs, God
A16	46	F	1	leader of a support group(NGO)-group has access to funds	rent income, husband works
A17	47	F	3	unemployed due to HIV/AIDS	piece jobs, other PLWHA, working brother, Pastor and other people, God

\*many of her children have died in infancy.

+estimated age

The transcripts were read several times. Themes were identified and the accounts of each interviewee were grouped in different categories according to the theme under which they fell. The verbatim transcripts in the themes are attached (cf. Appendix 3).

The accounts or life experiences of the people interviewed seemed to revolve around certain themes. These themes were psycho-emotional matters, work related issues, life after stopping work, finance and self-sustenance, stigma and discrimination, issues related to food, relationship matters, concern about children, spirituality, caregivers and social workers.

In the following section, the findings of the study are enumerated under the different themes. References are made to the thematically grouped interviewee accounts and to the original transcripts (available on request), where necessary, to illustrate or explain salient points.

### **Psycho-emotional matters**

Interviewees reported that their minds, behaviour, and emotions were affected by the status of having HIV/AIDS. As is illustrated below, interviewees had suicidal ideas, they had sleep disorders, they were bewildered, they felt like they were going mad, they were tormented by thoughts, they suffered delusions, anxiety, depression and social phobia. It is important to note that these terms are used loosely and not in their specific DSM definitions. The interviewees resorted to spirituality for support, comfort and to make sense of their situation. They also found that support from other PLWHA was very meaningful and healing.

#### **a. bewilderment:**

The interviewees reported that when one is told that he has HIV and or AIDS, it is like "leaving this world to enter a new world" according to A16<sup>45</sup>.

The person's personality changes such that he becomes this new person who has HIV/AIDS. "I am not able to be my natural self. I have now changed somehow..." says A14<sup>45</sup>.

A1 said that she did not know what was happening and that she felt like running away<sup>45</sup>. A3 also felt that she was not well but did not know what was happening to her<sup>45</sup>. A13 found that many things were happening to her physically and mentally. It was like her mind had changed<sup>45</sup>. A10 revealed how confused he was when he said, ".... about my life I don't understand how I am"<sup>45</sup>.

Thus having HIV/AIDS was described as a strange bewildering experience. The interviewee and the environment changed somehow when the interviewee was told that he was HIV positive. Thus the news birthed a new person and a strange or new paradigm.

## **b. sleep disorders:**

Interviewees described problems with sleeping, when they got to know that they had HIV/AIDS.

A1 related how going to sleep at night was a problem because she would feel like she was going mad<sup>45</sup>. She also had another problem that made her sleepless. "When you get to Tebelopele, you know, you are counselled first. I was telling myself that I had accepted myself. 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. I would be thinking at night because I was telling myself that I am ill for death (I was going to die). I was thinking a lot. I was telling myself that it has gone like that with me. This is where my life ends", she said.

A15 said that because of stress, she spent most of her time sleeping<sup>45</sup>.

## **c. the torment of thoughts:**

When interviewees discovered that they had HIV/AIDS, they were tormented by many thoughts that came to their minds.

A16 had this to say, "Even if you have been counseled, but if you 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 ...."<sup>45</sup>.

A17 thought about her children; what would become of them when she died<sup>45</sup>.

"I got out of 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, or what ....?". I was thinking along those lines". These are the thoughts that A15 grappled with after a doctor carelessly told her that she was HIV positive<sup>45</sup>.

".... also stress and talking a lot in my heart (anxiety) because of the way I was treated by my friends and my younger siblings", said A13<sup>45</sup>. Talking a lot in my heart can also be interpreted as thinking a lot. So A13 was also tormented by thoughts but these were a result of ill treatment by friends and siblings.

A12 thought he was going to die and this scared him. "Yes I thought I was really dead. It was the fear of death .... I thought I was going to die. I had not yet done anything. I am still young. I haven't done anything for myself," he said<sup>45</sup>.

A10's thoughts were affected by what people said of him. He suppressed these thoughts because he was afraid they could lead him to suicide. This is what he said, "well this is just mere talk which I am used to (i.e. harmless talk) because if I think a lot may be it can make me .... my heart .... want to kill myself or whatever"<sup>45</sup>.

Thinking a lot, in connection with their HIV status, also tormented A1, A7 and A8.

A1 could not sleep at night because of thinking a lot: "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. I would be thinking at night because I was telling myself that I am ill for death (I was going to die)"<sup>45</sup>.

"Since I got ill, what can I say is that I have the problem of talking in my heart (anxiety / depression / problems etc). I think a lot in my heart", said A7<sup>45</sup>.

A8 had painful questions in her heart (thoughts), about her sisters: "Yes I was asking myself, "Is it that they left me because I have this illness. They did not .... They were not able to .... It's like people don't accept their children when it comes to this kind of illness"<sup>45</sup>."

Thus we see that interviewees went through a lot of mental anguish after they were diagnosed with HIV/AIDS.

#### **d. delusions and wrong thinking:**

The study showed that interviewees had delusions and ideas about themselves and the disease, which were not necessarily true.

A1 thought that she was going to die; so did A12, A14 and A17<sup>45</sup>. Everybody dies eventually whether one has HIV/AIDS or not. Many PLWHA live meaningful lives for a long time with or without ARV therapy.

A10 thought that he was unable to do anything for himself when he said, "My life is not pleasant in the way I am ill because there's nothing I can do for myself."<sup>45</sup> When he was interviewed, he seemed to be in good health and fit to work to his capacity.

A11 was in denial. He said, "Me, I feel alright. There's no change at all"<sup>45</sup>. His life had changed a lot. He had been a lively social/party animal before, by his own admission. After he got HIV/AIDS, he became a recluse according to his own account.

A16 was also in denial when she was told that she was HIV positive; "The day I was told I had the germ, I did not even believe it", she said<sup>45</sup>.

A12 thought that PLWHA are sub-human. "... we people with HIV, if you compare us with people, you would think that we are not people"<sup>45</sup>.

A13 became paranoid. She said, "It was like at that time when people were talking, like when people were passing by and talking about HIV/AIDS, I would think that they are challenging me (provoking me)"<sup>45</sup>.

A14 thought that people could see that she had the HIV virus. She had not yet developed AIDS at the time she was interviewed. "It's like even if

somebody looks at you when you are just having a conversation, it's like the person notices that this person is sick", she said<sup>45</sup>.

A 15 thought that people who came to visit her when she was ill were not genuine. She felt they had just come to see the disease HIV/AIDS how it looks like. "Its like when you are a friend and you have come to pay me, the patient, a visit. My mind (the patients mind) tells me that it means that you know my disease. You have just come to see how I am suffering (how the disease is)"<sup>45</sup>.

**e. social phobia and reclusiveness:**

When interviewees got to know that they have HIV/AIDS they avoided social contact, for various reasons. The main reason seemed to be fear of discovery that one had HIV/AIDS. This made interviewees prefer to be alone.

A3 said ...."when a patient hides himself, sometimes it is because he does not want people to know his illness"<sup>45</sup>.

Although A7 knew that she was infected with HIV and was scared, she did not enlist the help of doctors: "... you know in the beginning it was frightening, people were scared. I did not proceed to ask doctors to help me or to give me pills"<sup>45</sup>.

A10 contemplated social isolation because of the mocking he was subjected to: "Yes I feel like separating myself from those who are able to (who like) .... speak about my things (about me), my illness like why am I suffering from this illness"<sup>45</sup>.

A11 turned from party animal to recluse: "Before I got ill, (he laughs). Before I got ill, I liked a fast life, grooving, you see (laughs). I lived a fast life, nice things / fun, and many other things like .... but now I have changed. I no longer go for these things. I just stay at home"<sup>45</sup>.

When A13 realised that she was infected with HIV, she became a recluse: "... I did not want people around me. I wanted to be alone"<sup>45</sup>. She had become paranoid and thought people were talking about her when they talked about HIV/AIDS.

A14 was very eloquent on social phobia. One of the reasons she gave for social phobia was that she felt people could tell just by looking at her that she was HIV positive. This made her uneasy in public. She also said ...."it is looking down upon oneself. You see you despise yourself. Then you become afraid of people. You fear communicating with people, you fear being in the midst of people"<sup>45</sup>. As an HIV infected person, she developed an inferiority complex, which made her shun social contact.

A15 isolated herself because when she was told that she had the HIV virus, she was stressed out. "I just stayed at home. Until this year I wasn't visiting anybody and I had a lot of stress about work, and life is also difficult. Before 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” she said<sup>45</sup>.

**f. anxiety and depression:**

Interviewee accounts demonstrated that they were anxious and depressed after they were diagnosed with HIV/AIDS.

A1 suffered a lot of anxiety at the beginning of her disease. This was partly due to the symptoms she had. “I felt like running away; so things like this make one talk by one’s heart (think a lot). It makes me talk by heart. You see I did not think my illness would take so long .... at first I hurt a lot. My heart was always painful”, she said<sup>45</sup>.

A2 had a difficult relationship with his nephew with whom he stayed. This caused him a lot of heartache. “No it is painful that when I talk about my nephew, who knows that I am his uncle .... not knowing that if I am running short in the house, then he does not know that he should help me”, he said<sup>45</sup>.

A3’s new status as a beggar was painful to her: “I live by begging, such that I do not stay well with a good heart”<sup>45</sup>.

A7 had a similar problem. Her anxiety was mostly due to her new state of helplessness: “Since I got ill, what can I say is that I have the problem of talking in my heart (anxiety / depression / problems etc). I think a lot in my heart. .... The main thing that troubles my heart is that, when we don’t have something, which I used to be able to provide for myself, I don’t feel all right. I think a lot and find that my heart is not all right”<sup>45</sup>.

A8 was troubled by the fact that her own sisters deserted her when she fell sick: “So I stayed with a painful heart. You see staying alone (without company) is very heavy (difficult). So .... I was asking myself really my sisters, why were they not visiting me”<sup>45</sup>.

A10 is afraid that he can get suicidal if he concentrates on the taunts of those who tease him about his illness. These taunts are a source of mental pain to him: “may be it can make me .... my heart .... want to kill myself or whatever. It hurts me in my mind (soul) because ah! I did not like that this illness should get into me. There’s nobody who likes it”<sup>45</sup>.

A12 was afraid that he was going to die. The news that he was HIV positive paralysed him such that he just withdrew from all activities. He may have been depressed: “For a month my heart was very sore (I was very sad). I was thin, I was dark in colour. I stayed for some time, not working, just sitting – doing nothing. Even work, I stopped working. I was just sitting doing nothing. I was thinking that I am really going to die”<sup>45</sup>.

A13 also exhibited symptoms that could have been of anxiety and or depression: “. I was having headaches and I liked to be alone. Sometimes my heart would beat. You see there were many things. Many things were happening to me... I did not want people around me. I wanted to be alone. When I realized that I had the germ, ....It was like my mind had changed”<sup>45</sup>.

A14 got into such a panic state that she became suicidal: "I did not feel comfortable with people. It's like even if somebody looks at you when you are just having a conversation, it's like the person notices that this person is sick. You just stay frightened and uneasy. Ok there came a time when I lost hope, telling myself that really now what am I living for"<sup>45</sup>.

A15 could have been depressed after she was told that she was HIV positive. She describes her state thus: "Before 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"<sup>45</sup>.

In the beginning of her illness A17 was afraid. She was also anxious about the fate of her children: "Really when I started, at the time I tested (for HIV), when they told me about my status (positive) it was like I was afraid. I thought about my children"<sup>45</sup>.

#### **g. spirituality:**

When interviewees realised they had HIV/AIDS, they placed their fate in the hands of God. This is not surprising because by their own accounts, interviewees felt that being diagnosed with HIV/AIDS was a devastating experience. No amount of counselling prepares one for a moment such as that: "... somebody will say "I have been counselled, and the way I have been counseled, if I am told that I am positive I can agree / I can accept". It is not that easy. .... It is not easy, because when you are told that you are HIV positive, .... You know .... I .... to me ..... it was like I was leaving one world/country and I was entering another world/country" said A16<sup>45</sup>.

A1 also felt that counselling does not adequately prepare one for the moment of truth: "When you get to Tebelopele, you know, you are counselled first. I was telling myself that I had accepted myself. 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"<sup>45</sup>.

This God was not defined but it can be assumed that this is the Christian God or the traditional Setswana deity. Most Batswana believe in either of the two. There was no indication that there was belief in some other God.

A4 enlists God's help to help him bare the pain of stigma: "... I never provoke another person. When they make fun of me or scold me, I just tell myself God is there"<sup>45</sup>.

A6 resigned her fate to God who knows everything: "I accepted myself and put myself before the Father of Lights (God). The Father of Lights knows each and everything"<sup>45</sup>.

A12 believed that he was still alive because of God's intervention: " I sometimes just say you know, God. If God was not there I would be dead already. Then I get hope when I read the Bible and get refreshed in my soul"<sup>45</sup>.

## **h. meaningful support from other PLWHA:**

he interviewees found the companionship of other PLWHA healing and meaningful.

A1 stopped hurting and realised that she would get well when she started spending time with other PLWHA: "... but now since I saw other people when I came here, at the hospice, I saw that I would get well as I see other people are getting well; like others have got better and have been discharged when I was here. So I see that no, this is an illness like other illnesses"<sup>46</sup>.

A3 life became better when she started spending her days with other PLWHA: "I spend the day with others. When I leave, I go home. The following day we come back etc. Now I live well"<sup>45</sup>.

A13 became relaxed and regained her self confidence when she joined a group of PLWHA: "When I came into the movement, I lost the obsession that I have the germ. I became able to tell people that I have the germ and I am on ARVs"<sup>45</sup>.

A14 felt that she was alive and like a human being after she talked to another PLWHA: "This one, she was the first person that when I told her, she took her time, and we had a conversation. At the end of the day I felt like yes I am a human being. I am like other people. I am alive and I can live much more"<sup>45</sup>.

A15's life changed for the better when she joined an organisation of PLWHA, which is run by PLWHA: "Since I got into this organization of Matlo go sha mabapi, you know, I feel good you know. I feel comfortable, it's not like before. It is not like before you know. Before I just spent all my time in the room, feeling pain and sleeping all the time"<sup>46</sup>.

A16, the leader of an organisation that serves PLWHA is a PLWHA herself. She says that her organisation teaches PLWHA to accept themselves (like themselves, learn to live positively): "When you start coming to our organization, I start by sitting you down and counseling you. I check and see the state you are in. But when I see that but no, you are doing this because maybe ..... we still deal with you mentally .... emotionally, so that you can accept yourself, because if you cannot accept yourself, nobody can accept you"<sup>46</sup>.

The utterances of other PLWHA and their good health gave A17 hope that she would get better: "I was told by people who are living with the germ, how .... you see I saw by the way they were. I myself, I was very ill that time. But when I heard how people maintained that they live with the germ but they take medication (ARVs), I looked at their condition. I accepted my fate and began to have hope"<sup>46</sup>.

## **Stigma and discrimination**

Stigma has been described as that quality that significantly discredits an individual in the eyes of others. Interviewees revealed that, unfortunately, the individual also ends up feeling inferior to other people. Interviewees

also revealed that they were laughed at and teased because they had HIV/AIDS. "They laugh when they see us eating these pills .... sometimes I hear some people teasing me/provoking me with some words...they say I am ill etc. I must go and listen to myself (rest) because I am ill", said A2<sup>45</sup>.

Interviewees were made fun of: "When they make fun of me or scold me, I just tell myself that God is there", said A4. "I do not know whether I am dirty or nauseating to them", was another comment that A4 made<sup>45</sup>.

A8 said that people do not like staying with someone who is infected with HIV: "... when this person hears that K .... has the germ, he will tell himself that hey, K .... it means it would be desirable she should not stay with us"<sup>45</sup>.

A10 said that people laugh at him when they hear that he has HIV/AIDS: "There are people who look at me and are able to say to me why .... laughing at me in the way they heard about this illness that is holding me"<sup>45</sup>.

A11 said that he has not come to a stage where he can tell people about his illness: "I feel that maybe people can become afraid of me / shun me or something, you see. I feel I would lose my friends"<sup>45</sup>.

A12 said that if you reveal your status to fellow workers, their attitudes towards you changes such that you may be forced to leave your job: "Like if you tell your workmate, later you find that they don't talk nicely to you. This is a problem because if I was not strong I could end up losing the job, leaving to go and look for a job elsewhere because the people at this workplace don't speak nicely to me"<sup>45</sup>.

A13 said that her siblings would not use the same eating utensils as herself: "I saw that when I handled something, when they ask 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"<sup>45</sup>.

A14 said that because of stigma, interviewees despised themselves. They were discriminated against because of stigma: "The main big thing that makes people not to live like other people is because of giving up hope. It is looking down upon oneself. You see you despise yourself It is the stigma. It is looking down upon oneself. It is stigma and discrimination"<sup>45</sup>.

A15 said that if you reveal your positive status people start treating you as a lesser being. " You see they will start to be nauseated by me and not taking me as a human being"<sup>45</sup>.

A16 said that in the beginning, PLWHA did not want to meet at her place at first because they did not want to be associated with HIV/AIDS: "At that time there was too much stigma. All these people did not want to be seen at my place. "No we cannot go to L's mothers place because L, all the people know that you are HIV positive. If we go there people will know that we have the germ (HIV)". Going to A16's place would reveal their HIV positive status they felt<sup>45</sup>.

A17 said that when PLWHA are still ill they are stigmatised even by other PLWHA: “during the time that they see that you are ill, .... you’re still ill, people don’t treat you well .... really even other patients .... it’s like if I, my condition ....I am alright, when I see somebody else coming in a poor condition .... me who is alright, I am able to look at this person....not looking at him well”<sup>45</sup>.

Some interviewees lost friends. “I had a friend but this friend when I told her, I saw that she developed a sly spirit. She was no longer free with me as before. So I ignored her and parted ways with her”<sup>45</sup>, said A15. A 8 said that she was abandoned by her sisters<sup>45</sup>. She continued to say that at times people prefer not to stay with PLWHA. Because of stigma, some PLWHA do not disclose their status. “I have not come to a stage where I can talk openly, telling somebody (about my illness). I feel I would lose my friends”<sup>45</sup>, said A11.

Some interviewees reported stigma in the work place. Other workers make life so unbearable that a PLWHA leaves or the employer fires him or refuses to take him back when he is better. “Like if you tell your workmate, later you find that they do not talk nicely to you. This is a problem because if I was not strong, I could end up losing the job ... . “because the people at this work place do not talk to me nicely”, said A12<sup>45</sup>. .... if someone is living with the germ, it is not common that they can hire him. If ever you leave your job because of illness, they don’t agree easily to give you back your job ....”, said A17<sup>45</sup>.

Refusal to share utensils and food was described. “I saw that when I handled something, when they ask 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. Sometimes when I left food and gave it to a child, they would call the child .... to make the child not to eat what I had given the child ....” said A13<sup>45</sup>.

Some interviewees said that being HIV positive was sometimes associated with prostitution. “Even when I am ill, I am afraid to tell people that I have the germ. It means that they will think that I am a prostitute; why do I have the germ?”, so said A15<sup>45</sup>. A16 echoed the same idea<sup>45</sup>.

It seems that the stigma of HIV/AIDS is decreasing. “At that time, there was too much stigma. All these people did not want to be seen at my place”, said A16<sup>45</sup>. A17 reported that her sister’s child who had HIV/AIDS was stigmatised whereas when she got HIV/AIDS later on, she was not<sup>45</sup>.

### **Work related issues**

When interviewees got ill there came a time that they could not cope with the demands of their work. Their bodies became too feeble for work or the other workers made life difficult for them at the work place.

“I was taken out of my job by my lack of good health”, said A1. “I saw that I could not cope and I saw that I was unable”, said A3<sup>45</sup>.

A2 stopped working because of illness also, "I am not working. I separated with work in 1999. I was ill"<sup>45</sup>.

A3 could not cope with the demands of her work when she got ill, "I was taken out of work because of illness .... I was working since 1990 and in 2004 it became impossible. I saw that I could not cope and I saw that I was unable"<sup>45</sup>.

A4, A6, and A7 also stopped working after they fell ill<sup>45</sup>.

The interviewees were forced to stop working because they became physically weak. "The body is light and ill such that even work, I don't see that I can work", according to A10<sup>45</sup>. Thus A15 and A17 stopped working too, as disease took its toll on their bodies.

A11 was on long leave because he was not fit for work<sup>45</sup>.

A14 was so stressed out when she was found to be HIV positive that she quit her job<sup>45</sup>.

Sometimes stigma and discrimination pushes them out of the workplace. A 12 said, ...."Sometimes at work these days, if you reveal your status, you end up losing your job. Like if you tell your workmate, later you find that they don't talk nicely to you. This is a problem because if I was not strong I could end up losing the job, leaving to go and look for a job elsewhere because the people at this workplace don't speak nicely to me .... "<sup>45</sup>.

Interviewees find that life is tough when they are out of work and cannot provide for themselves. "Now if there is no job, there is nothing. Like now, there is nothing I have", said A2<sup>45</sup>.

They long to find work as employed or self-employed people. "I have at times shed tears...because I strongly wish I was working", said A10<sup>45</sup>. "I wish I could get a job. This is the help that would satisfy me", said A15<sup>45</sup>.

A16 said that government does not seem to have a policy of empowering PLWHA by seeing to it that they get jobs. A16 felt that government was taking jobs from PLWHA and giving them to people of unknown HIV status<sup>46</sup>.

Some feel that government should help them to find jobs. .... there are councils .... they should look for jobs for us so that we can be trained", said A17<sup>45</sup>.

### **Life after stopping work**

When they got ill, interviewees soon stopped working, as has been stated above. They lost their source of income and life became difficult. Their standard of living fell.

A3 said, "No, since I got ill, my life has gone back"<sup>45</sup>.

“Now, the life I lead is a very lean life (difficult life)”, said A4<sup>45</sup>. “Life went backwards because even the things I had thought of doing were stopped because I could not work”, said A1<sup>45</sup>.

The PLWHA thus live a life of lack and this affects their health adversely. “The disease is very bad for people who are not able to help themselves, those who have nothing .... the body of the person changes all the time .... the weight is not alright etc ....”, said A12<sup>46</sup>.

They become dependent on relatives and friends for their upkeep. A3 said, “I can’t do anything for myself. Even when I go to hospital, I cry to my parents (beg for help/money)”<sup>45</sup>.

“I have a younger sibling who stays at Tsolamosese (Take off your dress - a township). Now she is the one who helps us by paying our rent”, said A7<sup>45</sup>.

“The old lady is the one who is letting out rooms. She is the one who is helping me with the maize meal which we eat together with the children”, said A10<sup>45</sup>.

This life as a pauper was described by A4 when he said, “Now when people come to check on me, they throw a coin at me (give me a little money) so that I can buy a drink”<sup>45</sup>.

Some interviewees take menial jobs and whatever job there is in order to survive. A13 said, “Sometimes I get a piece job to go and do washing for somebody”<sup>45</sup>. The same was echoed by A15 when she said, “I pay rent by doing piece jobs .... But it is not that we get these jobs everyday”<sup>45</sup>.

Some PLWHA got government assistance (food packages) through social workers but as the table shows only a few got this. This assistance programme has been modified by government such that only very ill patients benefit from it. The hospice has also assisted by giving food, clothing, transport and medical help.

## **Food**

When an HIV/AIDS patient starts treatment with ARV drugs, they soon develop a good appetite. The interviewees either felt like the HIV was eating the food they have eaten or the ARV drugs stimulated their appetite.

“I feel like eating frequently”, said A1. “The pills make me want to eat because if I have not eaten, I shiver”, she continued<sup>45</sup>.

A2 said that his illness requires that he eat: “The thing which is a real bother, the thing that really bothers me, it wants food (the need for food)”<sup>46</sup>.

A16 believes that HIV eats from the patient: “Because when you have the germ (HIV), it eats from the (infected) person”, said A16<sup>45</sup>. She said this to support the idea that PLWHA need adequate amounts of food: “It



seems HIV is more virulent in poor people.... To lack food is our death”, she also said<sup>45</sup>.

Unfortunately, interviewees did not have the resources to buy enough food to satisfy their hunger. “Like eating, I do not know where I will get food ....” said A2<sup>45</sup>.

“...now you will find that when it comes to eating, we eat once a day. Sometimes we do not eat at all”, said A4<sup>45</sup>.

A7 had nothing to eat so nurses went to social workers to ask for food support for her and her children: “Then they went to social workers so that I could be helped, because there was nothing I was eating and I am not working”<sup>46</sup>.

The thing that hurt A8 the most was that her sisters did not buy her food: “You see the thing that hurt me the most was even buying food, they were unable”<sup>45</sup>.

A12 said that what he needed most was food: “Food, clothing and food, these are the things I need a lot. The main needs are food etc”<sup>45</sup>.

A13 also expressed the need for food: “If they can help us with food and also find us jobs, it will be good”<sup>45</sup>.

A15 said that if hunger could kill many people would be dead:

(VS – What about food?)

A15 – “Hey! That’s a problem area. It’s a problem .... the saving grace is that hunger does not kill. Maybe we would have long died”<sup>45</sup>.

Interviewees were helped by volunteer organisations like the hospice to supplement their food resources, as A2 and A4 indicated<sup>45</sup>. Some interviewees (A3, A7 and A13) got food from the government, through social workers<sup>45</sup>.

Some who felt that they also deserved food relief from the government did not get it. “Even when you show social workers that there is this and this and this problem, they are not able to .... they just say, “We shall see, we shall see,” but it takes a long time .... and you do not get any feedback”, said A2<sup>46</sup>.

“Even now, the social workers say I should not go to them. I should wait for them but our food is running out”, said A6<sup>45</sup>.

“One time I went to the social workers to try to be on the list (for free food). Ah! They just give me advice saying-you try to .... because we social workers only help people who are very sick and incapacitated, those who are bedridden .... there are others who are very sick, and like me who have no food ....” said A15<sup>45</sup>.

The government has stopped food relief to many PLWHA. Those who are assessed to be not very ill are not supposed to get food relief.



“...as far as I have assessed, the great numbers of people who die because of HIV/AIDS, it is not because of HIV. Our problem is hunger. It seems HIV is more virulent in poor people. To lack food is our death”, so said A16<sup>45</sup>. She was stating the fact that ARV drug therapy needs to be supplemented by a good diet/food, for it to be effective.

## **Relationships**

When they got ill, interviewees lost their spouses. This is probably because their spouses knew or suspected that they have HIV/AIDS.

“The man I was living with, just when I started getting ill, before I tested (for HIV), he left. I think he left because he saw that I was ill”, said A17<sup>45</sup>.

The father of her child deserted A15 when she disclosed her HIV status to him: “The father of my first child he stays in Broadhurst. He just left me and went away”<sup>46</sup>.

When she got ill with HIV/AIDS, A13 says, “All things got spoilt; even the father of my children left”<sup>45</sup>.

A11 had this to say about the mother of his child, “As for now, we are out of touch .... because she has found another lover”<sup>45</sup>.

A10 also parted ways with his girlfriend, when he got ill: “She was told by other people. No we only meet in the way, but she does not visit me .... we are no longer together (lovers)”<sup>45</sup>.

A4 reported that his child’s mother and he had fallen out of love: “The child’s mother is there but we are not together”<sup>45</sup>.

Friendships are affected by HIV/AIDS. A4 and A12 were fortunate to retain their friends.

“I was a person who played football a lot before I got ill. So I had many friends who liked me. So when I am ill like this they come to visit me”, said A4<sup>45</sup>.

A12 retained his friends after he disclosed to them that he was HIV positive: “Even friends nothing has changed. They are still my friends”<sup>45</sup>.

A17 was fortunate to have friends who stayed with her ....”my friends ... mostly they are Christians. The children of God have not shown me bad behavior”<sup>45</sup>.

Other interviewees were less fortunate and they lost friends when they got ill.

It was sad to hear A1 say, “I would say that since I got ill, friends get out of you. Friends leave and you start living your life alone”<sup>45</sup>.

A13 had this to say, “Really when I started getting ill, and my illness got obvious, I found that there was not one friend who accepted me”<sup>45</sup>.

A15 parted ways with a friend when she observed that the friend was no longer friendly: “I had a friend but this friend when I told her, I saw that she developed a sly spirit. She was no longer free with me as before. So I ignored her and parted ways with her”<sup>45</sup>.

In some instances there were problems with relatives because of HIV/AIDS. Some interviewees felt deserted and unloved by their relatives.

“Even my siblings, they did not treat me like I was the child of their mother”, said A13<sup>45</sup>.

A8 was abandoned by her sisters: “Yes I was asking myself “Is it that they left me because I have this illness. They did not .... they were not able to .... It’s like people don’t accept their children when it comes to this kind of illness”<sup>46</sup>.

A4 and A2 also mentioned problems with relatives in their stories.

A2 was so bitter that he would not care for his nephew if the nephew got ill:” .... he does not know that he should help me. That is the bad thing and you find that even myself, if he were to get ill I would find myself not caring, as if he is not my mother’s child (relative)”<sup>45</sup>.

A4 complained that the young people in his home don’t take care of him: “Where I stay, eh – I am not well taken care of”<sup>46</sup>. They refused to wash and cook for him.

Some interviewees had supportive relatives. A3 said, “.... at home I am really well taken care of”<sup>45</sup>.

A6 had a similar report. “We at home really, we have a difficult life but we are in good terms (we hear each other)”, she said<sup>45</sup>.

### **How Interviewees experience the disease HIV/AIDS**

It is devastating to be told that one is HIV positive. “.... to me it was like I was leaving one world and entering another .... thoughts come...you will start blaming, denying, feeling ashamed, asking yourself where you got the germ, ...You start now recounting how many people you have had sex with...”said A16<sup>45</sup>.

It seems no amount of counselling adequately prepares one for such a time.

“When you get to Tebelopele, you know, you are counselled first. I was telling myself that I had accepted myself. 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”, said A1<sup>46</sup>.

A13 was counselled and she thought she could handle it if she was told that she had HIV infection. When the moment of truth came she was devastated. “ When I went for counseling, I was asked how I would feel if I was told I had the germ. I was checked for HIV when I had already accepted the outcome...And anger, short temperedness, and dizziness it was happening like that to me. I was having headaches and I liked to be alone. Sometimes my heart would beat”<sup>46</sup>.

A16 said that when one is told that he is HIV positive, the world, as one knows it, changes: “It is not easy, because when you are told that you are HIV positive, ...you know ... I ... to me ...it was like I was living one world/country and I was entering another world/country”<sup>46</sup>.

When asked to talk about their lives after they knew that they have HIV/AIDS, almost invariably, the interviewees started off by giving an account of their symptoms. They gave an account of how the diseases started and progressed. It was only on further probing and enquiry that they related matters concerning their social lives.

Interviewees felt that a lot of what has been said about HIV/AIDS in all kinds of media is frightening. HIV/AIDS has been portrayed as a vicious killer disease, and in the beginning, sufferers had no hope.

A15 said, “Really, this illness when it first arrived, people did not take it like any other disease. It was taken to be a devastating disease such that if you knew you had the germ, you would think that you would be dead the following day”<sup>45</sup>.

A14 said that what was said about HIV/AIDS when it broke into Botswana was frightening: “...the impact which this disease had when it entered (Botswana), the thing that was said about it, it is the thing that at the end of the day, this is the thing that makes us afraid to say “By the way I have this illness”... When it entered.... At the time you know there was no HIV. It was called AIDS. Now when it is said you have AIDS we know that you are already dead”<sup>45</sup>.

A12 too, has heard frightening news about HIV/AIDS: “They talk a lot about HIV/AIDS as being a dangerous enemy, a big dangerous enemy. They don't say it is like other diseases ...talking lightly like other diseases. They say it is an illness that takes you to death...”<sup>45</sup>.

A7 said that in the beginning, HIV/AIDS was a frightening disease: “.... you know in the beginning it was frightening, people were scared. I did not proceed to ask doctors to help me or to give me pills”<sup>46</sup>.

This also made it difficult for interviewees to disclose their status. “...this is the thing that makes us afraid to say -By the way I have this illness”, said A14<sup>45</sup>.

Interviewees described many symptoms of their disease. They described chills, dizziness and fever.

“I started feeling cold at work...then I moved to another side because of dizziness and fever”, said A1. A1 also described feelings of going mad<sup>45</sup>.

A13 also had a fever, feeling cold and she had difficulty in breathing: “I had fever, difficulty in my breathing, and feeling cold. I thought it was only flu”<sup>45</sup>.

Some interviewees got paralysed.

A1 found that she could no longer walk without support: “After I started talking these pills, my feet started...when I tried to stand up I would fall down. I had to be supported to go to the toilet”<sup>45</sup>.

“...like I could not walk, my toes were curled up like this,...not speaking, with my teeth tightly clenched...feeding me with a tube very thin porridge...breathing oxygen”, said A6<sup>45</sup>.

A8 got paralysed too: “I could not walk, I could not do anything for myself”<sup>45</sup>.

Half of A11’s body was paralysed: “I was paralysed ....half of my body”<sup>45</sup>.

Some interviewees developed pulmonary TB. Some of those who developed TB described dyspnoea and chest pain.

A1 is one of those who developed TB: “I had already been put on anti TB drugs also”<sup>45</sup>.

A6 had TB, chest pains and difficulty in breathing: “they said I had TB and they told me that I also have the germ (HIV). I have difficulty breathing, making me breathe with painful heaviness, ....having difficulty in breathing with the sharp pain blocking”<sup>45</sup>.

A8 was put on anti TB therapy also: “I was taking TB treatment”<sup>45</sup>.

A13 said, “I had fever, difficulty in my breathing, and feeling cold ....I thought it was only flu ....I was checked for TB... It was found in the pain, in the chest”<sup>45</sup>.

Some interviewees described side effects of their treatment. They had rashes, pain and some became more ill after commencing anti TB drugs and/or ARV drug therapy.

A1 thought that treatment made her worse: “After I started talking these pills, my feet started...when I tried to stand up I would fall down.... But when I reduced anti TB drugs (the pills), I saw that things got better ...”<sup>45</sup>.

A3 said that ARV drug therapy is too strong for patients who are very ill: “....because the patient would have been ill a long time. When he comes to take these treatments they can’t help him because they are too strong for him”<sup>45</sup>.

A8 thought that the pain in her legs was due to anti TB therapy: “Because I was taking TB treatment, I was having pain in my legs-they were swelling and I could not walk”<sup>45</sup>.

“Then I continued taking anti TB pills. They made me get a rash; having swelling of the body and swelling of my private parts”, said A13<sup>45</sup>.

A17 said that she suffered from side effects for eight months<sup>45</sup>. “They told me that at the beginning, the drugs I was taking could make me feel more ill”, she said.

Some interviewees felt that ARV drug treatment is effective if it is started early in the disease.

“The disease only kills if by the time you get treatment, you are already very low ....”, said A2<sup>45</sup>.

A3 felt that people should seek help soon after they realise that they are not well: “What is necessary is that as soon as you feel ill you should seek help”<sup>45</sup>.

They also said that for it to be effective, it should not be mixed with “other things” (referring to traditional medicine).

“As long as you continue your lullers (ARV therapy), you cannot feel any pain in your body...if you continue with these lullers, drinking them, not mixing them...don’t mix them with bad things in secret”, said A6<sup>45</sup>.

A17 said that those who continued to take Setswana medicine or alcohol died of HIV/AIDS: “....some will tell you, “take Setswana medicine together with ARVs it is alright.” Some will tell you that. Some say “I drink alcohol. It does not matter if you take ARVs while continuing to drink alcohol. It doesn’t matter.” But then, those very people, they don’t live. I mean that they are dead now”<sup>46</sup>.

### **Concern about children**

Most of the interviewees who had children were concerned that they were no longer capable of taking care of their children’s needs. The concerns were around school requirements, food, and who takes care of the children after death. They felt that they were responsible for their children.

“I must know what I can do with the children”, said A2<sup>45</sup>.

A1 passes onto her children whatever money she can get: “Sometimes I get money when someone comes to visit me and says, “Take this; you will buy yourself some fruits.” I take this money and pass it on to the children”<sup>45</sup>.

A7 was concerned that she could not help her children: “Now these days I see that, the children, they live a hard life because I struggle. I am not able to do anything that can help”<sup>45</sup>.

A15's problems stem from the fact that she can't provide for her children: "If it was not for school children, I would not have a lot of problems that stress me ....if you are not working and you are told, "your child needs this, your child needs that", the child also cannot learn well at school"<sup>45</sup>.

"I thought a lot about my children...So I thought "really if I leave them and die ...because I know that this illness called AIDS kills, if I die how will they live", said A17<sup>45</sup>.

### **Care-givers and social workers**

The interviewees expressed their feelings regarding those who took care of them during their illness. The caregivers included relatives, the hospice, social workers, a pastor, nurses and doctors.

Relatives included parents (both biological and cultural), brothers and sisters, cousins, nieces and nephews. Cultural parents are those adult relatives, usually of the same age as one's biological parents or older living in the same community as the index person. In its most liberal definition, either it includes all people of the same age as one's biological parents or older, or all people who are capable of looking after the index person.

Some relatives were good caregivers.

"At home, really, there is no problem. Really there is nothing I can complain about (at home)", said A3 who was staying with her parents<sup>46</sup>.

A14 said, "I have not had a difficult life because the many rejections one hears about I have not suffered them really. Even at home, with my parents also, when I told them there was no rejection"<sup>46</sup>.

Some relatives were bad caregivers.

"Just now, you see, I stay with my nephew...As for me, honestly he is far away from me...No, he is completely unable (useless)", said A2<sup>46</sup>.

"My sisters did not take care of me as my mother would have if she was still alive. You see staying alone (without company) is very heavy (difficult) ....I was asking myself, really, my sisters, why were they not visiting me ....", said A8<sup>46</sup>.

Some interviewees stayed with both good and bad care givers who were also related to them.

This is illustrated in A4's account: "Where I stay, eh, I am not well taken care of. You see it is my aunt who takes care of me. She is the only one who is helping me...These young people who stay at home, when I ask them to wash for me they don't agree. Sometimes when I ask a person (the young people) to make me porridge, they refuse ...."<sup>46</sup>.

A13 said, “Really when I started getting ill, and my illness got obvious ....I was accepted by the parent who breast fed me (biological mother). Even my siblings did not treat me like I was the child of their mother”, said A13<sup>46</sup>.

Some relatives developed caregiver fatigue.

“It means the one who is looking after me is now tired. They shout angrily. They say I eat a lot”, said A1.

Some health care workers were bad caregivers.

“....the doctor who told me my results; really he did not tell me in a pleasant way. He came with my cards from the room where you get results and threw the papers (on the table) and said, “Ah you lady of Botswana ....I don’t know how you are. See now you are HIV positive”. Then he threw the paper of my results at me, like this ....Ah! Ah! You know I got very frightened. My heart was very sore”, said A15<sup>46</sup>.

Some healthcare workers showed compassion and care. A4 said, about his doctor:” Then he asked if I had problems and I said yes. He asked what my problem was and I told him that I do not have money for transport. Then he gave me money and said, “Take this money and come”<sup>46</sup>.

Some interviewees felt they were helped by social workers while others did not.

“....The very social workers ....it’s like ....it’s like they don’t care to assess ...but really your health may be better but the means to support oneself may be absent completely. It’s like they don’t care ....if you are not well ....if you are well, you are all right (to fend for yourself) they leave you”, said A17<sup>46</sup>.

“Even when you show social workers that there is this and this problem, they are not able to ....they just say – We shall see. We shall see- but it takes a long time ....and you do not get any feed back”, said A2<sup>46</sup>.

A6 said that the social workers were refusing to give her food: “The social workers are also refusing to give me food. I do not know why they refuse. Sometime ago, they (doctors) made me a letter that said I should go and get free food”<sup>46</sup>.

“....As for food I don’t have much of a problem because I am given food at the council (Gaborone City Council)”, said A3 who was assisted by social workers to get food relief<sup>46</sup>.

A7 was also helped by social workers to get food relief. “Then they went to social workers so that I could be helped, because there was nothing I was eating and I am not working. Then they helped me in the month that has just ended”, she said<sup>45</sup>.

The hospice helped interviewees with food and other assistance.

A2 depended, to a large extent, on the hospice for food: "I live by eating here (at the hospice)"<sup>45</sup>.

A4 said, "Now I am only helped by coming to the hospice so that I can eat better food. If it was not for the hospice, I do not know what I would do"<sup>45</sup>.

A3 said, "...here (hospice) also I receive help ...."<sup>46</sup>.

A10 also said that the hospice provided second hand clothing at times<sup>46</sup>.

The accounts of the interviewees show that having HIV/AIDS is a traumatising experience. The disease ravaged their bodies such that they lost control of limbs and mental faculties. They indeed lost control of their lives as they lost jobs and the ability to look after themselves and their dependents. The disease made them acquire new and strange identities as despised, inferior people. This changed their world into a smaller environment as they developed social phobia. Relationships with siblings, spouses and friends changed or broke down. All these onslaughts on their lives resulted in emotional, psychological and sometimes psychiatric problems.

These accounts show that HIV/AIDS is a complex, multifaceted disease.



## **CHAPTER 5: DISCUSSION**

In this study people who were known to have HIV/AIDS were interviewed using the in depth interview method. The interviewees gave accounts of their experiences after they discovered that they have HIV/AIDS. This part of the study report, is a discussion of the findings of the study.

The findings of this study were similar to those of other studies on the effects of HIV/AIDS on the lives of PLWHA. Thus the study revealed that HIV/AIDS made interviewees poor and destitute. Interviewees reported stigmatisation and loss of jobs. They lost friends and spouses. They lived in poor congested housing and they needed jobs and food. Psychological, emotional and psychiatric problems were common among interviewees.

Though the study confirmed what is already known about HIV/AIDS. It also revealed some aspects of this disease that seemed to be unique to the Botswana context. These are characteristics of HIV/AIDS that were not revealed in the literature review.

There was a big concern about hunger and food. The interviewees developed very good appetites after starting ARV therapy. Unfortunately they did not have the means to get enough food. They suffered hunger as a result. The interviewees felt that the germ (HIV) devoured the food they had eaten.

The interviewees felt that the media and other sources of information gave very frightening accounts of HIV/AIDS. They felt that this had been the case in the first few years of the epidemic in Botswana. Instead of being empowered by the information they got, they felt frightened and hopeless. This had implications on disclosure. The interviewees did not want to be known to be harbourers of such a dreaded disease.

The study revealed first hand descriptions of symptoms of HIV/AIDS from interviewees. They reported mental and physical symptoms of HIV/AIDS that seemed unique. They were bewildered and perplexed by the disease as it took its toll. They did not know what was happening to them. They felt that they were going mad. They reported paralysis or weakness. Chest pains and TB were common. These symptoms were often described in bizarre ways. The effects of taking alcohol or traditional medicine were also described.

A detailed discussion of the findings, catergorised into the different themes, follows.

### **Demographics**

All the people who were interviewed were adults and their ages ranged from 28 to 47 years. The average age was 35.3 years. Thus, this was a fairly young group. This is in line with the fact that HIV/AIDS is mostly a disease of young adults who are at the prime of their lives.

There were more women than men in this study (10 women and 5 men). This has been a characteristic feature of the Botswana epidemic.

According to UNAIDS, more women than men are infected with HIV, in Botswana, Zambia and Kenya<sup>47</sup>. The same is true of South Africa, where the overwhelming majority of those infected are young African women<sup>48</sup>. More women than men are coming forward for testing and also more women than men are being treated for HIV/AIDS. Since transmission is probably mostly by heterosexual intercourse in this part of Africa, maybe the female genital tract is more vulnerable to HIV infection than the male. Heath and Rodway state that women are ten times as likely to become infected, through unprotected anal or vaginal sex, than to transmit the virus to their partner<sup>11</sup>. The use of caustic chemicals, by some females, to make the female genitalia dry, renders them more vulnerable to injury during intercourse and thus more susceptible to HIV infection. Male circumcision is protective against HIV infection whereas there are no such reports about female circumcision. Socio-cultural practices also expose females to sex and HIV at an earlier age. The same practices also make males play a dominant role in decisions about sex<sup>49</sup>. Violence, threat of violence, fear of abandonment, lower social status and the subordinate position of women in Botswana makes it difficult for females to protect themselves against HIV infection<sup>49</sup>.

Walker and Gilbert state that disease prevalence reflects social imbalances in society<sup>48</sup>. In their very important paper, Walker and Gilbert elaborate what several different studies have shown before; that gender, social class, race/ethnicity, and sexuality put women at increased risk of HIV infection. They further argue that in the South African context, gender, race, and poverty are central in shaping women's risk to HIV infection. That is why in "in conditions of poverty, girls often depend on sexual partners for gifts such as money or clothing, and have limited power to insist on condoms in such contexts<sup>50</sup>."

One would posit that these same factors (societal imbalances due to gender, race or tribe, and income) are also making more women than men to have HIV/AIDS in Botswana. Thus any HIV/AIDS prevention measures that do not take these factors into account are simplistic.

All the interviewees came from the high density, poorer townships of Gaborone. One of them was letting out rooms, in a poor neighbourhood, which she had inherited from her deceased parents. Some were staying in their parents' or relatives' properties, sharing a room with other relatives. The rest were staying in rented rooms, which they shared with other people. Thus most of these interviewees were staying in congested rooms in the poorer sections of Gaborone where water is collected from communal taps in buckets to be used in the home. In most cases the toilet is a pit latrine outside the house. With many people using such a toilet, it is often difficult for anybody to take the initiative to clean the toilet. Thus most of the interviewees lived in poor unhygienic circumstances.

That almost all the interviewees came from the poorest neighbourhoods of Gaborone may be due to the localities where the interviewees were sourced, that are in the poor areas of Gaborone. Since most of the interviewees themselves were poor and out of work, they would naturally locate themselves in the poor sections of Gaborone. There is also a

possibility that most of the interviewees had HIV/AIDS because of the societal imbalances which Walker and Gilbert cite.

Only one of the interviewees was married at the time of the study. One interviewee said that her husband had died. Since none of the nine unmarried women had a steady job, this has implications on the spread of HIV/AIDS. Unemployed females may be tempted to sustain themselves and their loved ones by becoming sex workers. They may also attach themselves to men for material and monetary favours. These practices promote the spread of HIV/AIDS. This is because some men prefer unprotected sex. The sex workers and women who attach themselves to men for material and monetary gain are in the unenviable position of losing their means of livelihood if they refuse unprotected sex.

All but four interviewees had children. Two of the four male interviewees had children, while nine of the eleven female interviewees had living children.

For the 15 interviewees, each one had, on average, 1.6 children. The 10 interviewees, who had living children, had, on average, 2.4 children each. One of the females who did not have children had lost all of her children in their infancy. This could have been due to HIV/AIDS and, or, to the unhygienic, impoverished conditions in which the interviewee lived.

This means that only one of the female interviewees had not had a child. In Botswana, most people have had a child by the time they are twenty eight (the youngest interviewee in the group). It is not common for a person not to have a child when they are 35.3 years old (the average age of this group). Education may be affecting this practice as more and more people postpone having children in order to acquire skills in their chosen career. HIV/AIDS may also be affecting this statistic as more and more people use condoms (a form of contraception) to protect themselves against HIV infection.

As already established above, almost all of the interviewees were unmarried. Thus most of the children were born to unmarried parents. In this kind of situation the mother bears the child and it would be difficult for her to deny or not to know that she is the mother of a child. Thus all but one female interviewee said that she had children. Men on the other hand may not know that they are the parent of a child. This may be due to the fact that the mother has multiple male partners. Males may also deny parenthood for a variety of reasons. Thus only two of the male interviewees said they had children.

All the interviewees were not working. This is similar to Kalane's<sup>24</sup> findings that when PLWHA became sick or disclosed their status, they lost their jobs. One interviewee was a policeman who was on long sick leave. He was receiving half of his usual salary from his employer and he complained that this was inadequate. One was the leader of an NGO which receives funding from government and other donors. Some were scraping a living from doing odd jobs/piece jobs (if they were well enough), which they got sporadically. Mostly they were dependent on relatives, government, non governmental organisations and friends for their upkeep and the upkeep of their children. Thus they were people who

were destitute in most cases. This reflects one of the impacts of HIV/AIDS on communities. It impoverishes them. Poverty and reduced income is indeed one of the major outcomes of HIV/AIDS in a community as Bolton and Milk<sup>6</sup> found in their study. Kalane (mentioned above) says that in Botswana, when PLWHA got sick or disclosed their status, they lost their jobs and their financial freedom.

Most of the interviewees lived in congested poor housing conditions. Stajduhar and Lindsey also had similar findings in their study in the United States of America<sup>30</sup>. They found that PLWHA have no housing, are about to lose their housing, or require a different type of housing.

Although most of the interviewees came from the poorer sections of Gaborone, when they got ill, they were forced to leave their own housing and move in with their relatives in the same kind of locality. This resulted in congestion since relatives themselves, had humble dwellings in a poor neighbourhood.

Some did mention that they depended on God to see them through the misery of their disease. This is a common feature among HIV/AIDS patients as already discussed under Spirituality in the literature review.

### **Psycho emotional matters**

The study showed that when an interviewee was told that he is HIV, he entered a new world. He became a new person who is stigmatised and looked at unfavourably by members of his community. This new status was bewildering, as if the interviewee could not believe or understand what had befallen him. It seems that no amount of counselling adequately prepares a person for the moment that they are told that they are HIV positive. This reaction is similar to the findings of Newton<sup>21</sup> among nurses, in the United States, who had suffered high risk HIV exposure (needle prick or body fluids). The nurses were devastated by the experience despite the fact that they were professionals who probably counselled patients themselves.

Interviewees in the study suffered from anxiety. They thought about dying and that the end of their lives had come. In their Indian study, Joseph and Bhatti report that women in their study had constant thoughts of death and dying<sup>15</sup>. In Canada, Heath and Rodway found that fears regarding their premature death were prevalent among women in their study<sup>11</sup>. In the Gaborone study, some interviewees could not understand why they could die so young when their lives had hardly begun. They worried about providing for their children. Their new despised social status caused them emotional pain as they grappled with shame of their disease. They were tormented by many thoughts and some even thought that they were going mad. These tormenting, distorted thoughts were generated by their painful experiences as PLWHA, as well as the brain diseases, which were caused by HIV/AIDS. Thus the interviewees suffered an avalanche of painful thoughts that were connected to their HIV status. This made them feel like they were going mad and that they did not know or grasp what was happening to them. This also added to their anxiety and bewilderment.

Some interviewees developed paranoid feelings and delusions. They felt that whenever anyone spoke about HIV/AIDS, they were referring to them. Some felt that visitors were not genuine. They felt that they had just come to satisfy their curiosity about HIV/AIDS. Some interviewees thought that people could tell that they were infected with HIV, just by looking at them. Some interviewees began to wonder if they were nauseating or subhuman. This was in response to the way that they were being treated. Thus they had become vulnerable and insecure. Low self esteem and perceived lack of power were dominant themes in the study on HIV infected women in Canada<sup>11</sup>.

These many, confusing, painful thoughts caused sleep disorders. Some became sleepless. Some slept a lot more than before they got diagnosed with HIV. They slept a lot because they were just paralysed by thoughts and their new status as PLWHA.

With time, interviewees became engulfed in a cloud of shame and secrecy about their disease. They developed social phobia and became recluse. This was to minimise the stigma they suffered from their communities and to guard against discovery of their HIV status. Joseph and Bhatti had similar findings in India where they report that HIV positive women, whose husbands had HIV/AIDS, minimised their social interactions<sup>15</sup>. Posel states that AIDS elicits responses of shame, hiding from other people and secrecy about one's disease<sup>10</sup>.

A few studies have already been referred to in the literature review section above, that show that PLWHA have psychological, emotional and psychiatric problems. These are, (i) Gil, Arranz, Lianes and Breitbart, (ii) Anderson and Doyal, and (iii) Frank, Bhindo and Brabant.

Some interviewees became depressed and had to battle against thoughts of committing suicide. This is not surprising because as has been shown above, they were under intense mental and psychological strain. It is no wonder then that interviewees also turned to God for comfort and support. As they did not understand what was happening to them, they said that God knows. They believed that God knew about them and trusted Him to look out for their welfare under all circumstances. Heath and Rodway in Canada<sup>11</sup>, and Joseph and Bhatti<sup>15</sup> in India found that religion and spirituality were important coping mechanisms in women infected with HIV. HIV/AIDS puts people at end of the road, between a rock and a hard place, and when all else falls apart, people turn to God.

It is interesting that despite all these problems, none of the interviewees mentioned being given psychological or psychiatric treatment, not to mention by a professional. The health authorities in Botswana have made a good start by instituting counselling around HIV testing and exposure. There seems to be a need for full psychological and psychiatric support for PLWHA. This support should be at a professional level as shown by the problems they suffer from. This will be a big challenge to the already overstretched health infrastructure.

## **The company of other PLWHA**

One very important conclusion that one can draw from the study is that interviewees found the company of other PLWHA very meaningful and healing. This is because they need “someone to listen to my concerns”<sup>11</sup> and understand. They need “someone to be there with me”<sup>11</sup> who has been where they are. Interviewees found the company of other PLWHA healing because they shared a common predicament and understood what each of them was going through. This may also have been because they could be free of shame and the burden of secrecy amongst fellow sufferers. The most important factor in finding comfort in other PLWHA’s company must have been meaningful sympathy that was perceived as genuine. Some interviewees stated that, quite often, those who visited them, who were not PLWHA, reduced them to spectacles or objects of curiosity.

## **Stigma and discrimination**

Interviewees showed that they suffered stigma and discrimination by family members, friends, employers and members of their community. This was evidenced by uncomplimentary remarks at work and in the neighbourhood. There was fear of sharing eating utensils with interviewees and some of them reported that relatives would hide PLWHA because of the shame that HIV/AIDS brought to the family. Anderson and Doyal have also shown in their study that HIV/AIDS is a very stigmatising condition<sup>7</sup>. They found that as a result of stigma and discrimination, interviewees lost self-esteem, became reclusive, they lost friends, and family ties got disrupted. Stigmatization also leads to interviewees losing jobs and fearing to disclose their status. The literature review part of this report refers to studies by <sup>1</sup>Kgakole, <sup>2</sup>Letamo, <sup>3</sup>Boer and Emmons, and <sup>4</sup>UNAIDS which showed various forms of stigmatisation. It is important to note that two interviewees, who had not yet developed AIDS, mentioned that they had not suffered stigmatisation. Perhaps this indicates that PLWHA are stigmatised when it becomes obvious that they have HIV/AIDS.

It would seem that with the passing of time, stigmatisation of PLWHA is decreasing as was indicated by some interviewees. This may be a result of familiarity as HIV/AIDS has become commonplace in Botswana. With the high prevalence rates in the country, many people have been infected. Many people are also affected by HIV/AIDS, as there is hardly a family that has not suffered a victim of the disease. The decline in stigmatisation could also be due to public education about the various aspects of this disease.

## **Work related issues**

When interviewees got ill, they found that their bodies could not allow them to continue working. They became too weak to work. Mast et al also found that HIV infected women find it difficult to work<sup>23</sup>. They found that even minor jobs are difficult for them when they are ill. Thus interviewees soon lost their jobs when they got ill. When they got better it was difficult for them to get their jobs back.



Stigmatisation and social phobia were also mentioned as reasons for job loss. This study confirms the high unemployment rate among PLWHA, which Dray-Spira et al found in their study in France (50%). Busang and Tharakan also found a high unemployment rate among PLWHA in Botswana (49%). The almost 100% unemployment rate in this study could be due to the characteristics of the interviewees. Most of them were either in the early to intermediate stages of recuperating from a serious illness due to HIV/AIDS. They also came from the lower end of the social strata. This means that they did menial jobs as housemaids or unskilled labourers in construction companies and factories. In these kinds of jobs in Botswana, there is very little job security. Unemployment is also usually highest in the unskilled sector.

### **Life after stopping work**

When they stopped working, interviewees found that their lives deteriorated. They could not support themselves and their dependents (mostly children and parents). Their lives became difficult. Bolton and Milk<sup>6</sup>, in their study in Uganda, also found that poverty and reduced income is indeed one of the major outcomes of HIV/AIDS in a community. Kalane's in Botswana found that HIV/AIDS makes sufferers lose their financial freedom<sup>24</sup>. Thus interviewees lived in utter poverty and lost the power to provide for themselves. They lost financial freedom to live their lives as they wished.

The interviewees became destitute and dependent on relatives and the government after losing their jobs. They did not like this. They preferred that they could get well and start working for themselves. Anderson and Doyal found that most African women living with HIV in London, disliked taking benefits and preferred to work and support themselves<sup>7</sup>. Interviewees in this study preferred government to find them jobs and or train them for jobs. One wished government could empower known PLWHA by directing jobs to them.

The government of Botswana recently stopped food aid to many PLWHA. This leaves many PLWHA in dire straits.

### **Food**

"....as far as I have assessed, the great numbers of people who die because of HIV/AIDS, it is not because of HIV. Our problem is hunger. It seems HIV is more virulent in poor people. To lack food is our death", so said A16<sup>45</sup>.

This statement has haunted the interviewer since the very first time he heard it from a very thin lady who has HIV/AIDS. It is haunting because it is true. It is also haunting because this lady (A16), who only has two years of secondary school education, made an observation, which is substantiated by studies. Frank, Bhindo, and Brabant from their study in Louisiana, USA, found that lack of food may lead to early deaths in women who have AIDS<sup>17</sup>. Brown and Boag state that observational studies have demonstrated that micronutrient deficiencies in HIV positive individuals are associated with faster progression and mortality<sup>26</sup>. Andrews, is a doctor who attends to HIV/AIDS patients in Cape Town,

South Africa. He was accompanied by a professor of medicine at the University of Cape Town in a lecture tour of Botswana sponsored by a medical aid company. He writes that nutrition remains a cornerstone of HIV management and advises that nutritional intervention and dietary recommendations should be started early<sup>28</sup>.

Interviewees developed very good appetites after starting ARV drug therapy. They thought that this was due to the HIV eating the food they had eaten or that the ARV drugs stimulated their appetites. Unfortunately the interviewees did not have the resources to satisfy these good appetites. They depended on NGOs and government food aid to supplement their food requirements. Unfortunately government has stopped its food aid to many PLWHA and the one NGO that was cited only gave them one meal three or four days a week. This means that if the circumstances of the interviewees have not changed, they are underfed. This may mean that lack of food is working against their ARV drug treatment, leading them to disease and death.

## **Relationships**

HIV/AIDS affliction affected the relationships of the interviewees. Relationships with spouses were negatively affected. In most cases, relationships ended when one spouse got ill. This is probably because almost all of the interviewees were not married. The healthy spouse probably left because they realised that their partner had AIDS and they did not want to be associated with the disease or to be infected. The long spells in hospital and in one case (A11), relocation to another region of the country negatively affected the relationship.

Friendships ended when the interviewees got ill. This may have been due to stigmatisation; friends being afraid that they will get infected by an ill friend, or not wanting to be associated with HIV/AIDS. Some interviewees became reclusive, paranoid and or developed social phobia. This would put a strain on friendships.

Frank, Bhindo and Brabant found that women with HIV AIDS were rejected and isolated<sup>17</sup>. Anderson and Doyal also mention that husbands or partners rejected their women, because they were HIV positive<sup>7</sup>. Kgakole (see above) also mentions that PLWHA are isolated in their families and at social functions<sup>14</sup>. All these studies confirm the problems that the interviewees had in their relationships. Joseph and Bhatti cite communication, sexual and other marital problems experienced by HIV positive wives of men with AIDS in India<sup>15</sup>.

Some interviewees had very supportive families and relatives. This would be expected of the extended family and the practice of "botho/ubuntu". Ndinda et al mention, in their findings on community attitudes towards PLWHA<sup>51</sup>, some desirable attitudes. "The desirable attitudes in the family included treating the infected well and supporting them, meeting their emotional, material, and spiritual needs and supporting them", reports Ndinda et al. It is important to note that Ndinda et al's study was in a rural context in South Africa. It is likely that attitudes in urban contexts would be different because of the different lifestyles and pressures. HIV/AIDS is unfortunately beginning to destroy this practice



(botho/ubuntu) especially in urban settings. In this study, which was in an urban setting, some interviewees suffered rejection, desertion and stigmatisation at the hands of their own kin. Kgakole had similar findings in his study in Botswana<sup>14</sup>. One can no longer take for granted the support of the extended family for PLWHA. This crumbling of the extended family support and botho/ubuntu could also be associated with the emergence of the nuclear family in urban areas. Scant resources among poor folk (of whom the interviewees were a part) also make it difficult to share.

Ndinda et al suggest that community members know how PLWHA should be treated but practising this is a challenge.

### **How Interviewees experience the disease HIV/AIDS**

When the interviewees were asked to relate their stories after they got to know that they had HIV/AIDS, they invariably started by giving an account of their physical illness. This could have been because they attached great importance to their physical well-being. It could also have been because they thought that this was the expected response.

The interviewees described chills and fever, faintness, and body weakness. These symptoms could be attributed to most infective diseases including HIV infection itself and other diseases that are consequential to HIV infection. Chest pains and difficulty in breathing were described and these could have been due to pneumonia or PTB from underlying HIV/AIDS. Paralysis, and not being of aware what was going on could have been due to encephalitis, meningitis and other brain afflictions that are common in HIV/AIDS. All these symptoms and signs of HIV/AIDS can be found in any standard textbook of medicine.

The interviewees also gave accounts of problems of an emotional, psychological, and psychiatric nature. Thus HIV/AIDS is not only a physical disease. It is also a disease of the psyche and emotions. This aspect of the disease has already been discussed above.

### **Concern about children**

The interviewees were concerned that they could no longer provide for their children. They were distressed that their children could no longer get what they used to provide for them before HIV/AIDS cost them their jobs. Another area of concern was about how to break the news to children; that one was HIV positive. One interviewee was distressed about what was going to happen to her children if she died.

Joseph and Bhatti found that children were a main source of concern in their study of women who were infected with HIV, in India<sup>15</sup>. They were concerned that their parenting efficacy had decreased, that they would infect their children, that their children's education would be interrupted and they were afraid of the premature death and isolation of their seropositive children.

Frank, Bhindo and Brabant found that women have to deal with the problems of dying and leaving their children, and of having infected their

children<sup>17</sup>. This study, which was made in the USA, did not mention any concern about providing for children. This is probably because there is a secure social welfare system, especially for children, in that part of the world. The interviewees in this study did not exhibit any self blame about the possibility of having infected their children or the possibility of dying and leaving them behind. In this society (Botswana), the interviewees probably felt that they were victims themselves and that they deserved sympathy and compassion.

### **Care-givers and social workers**

Relatives, friends, a pastor, an NGO, nurses and doctors cared for interviewees. Some caregivers were good while others were bad. Some relatives were good caregivers while others were bad. Ndinda et al mention “a co-existence of binary oppositions”, that is a combination of good and bad care givers. Botho/ubuntu dictates that a sick person is taken care of with love. The onslaughts of urbanisation, modernisation, poverty, emergence of the nuclear family, decline of the extended family, and HIV/AIDS stigma seem to be eroding this noble practice. Thus one cannot be sure if the family is going to be there for him when he gets HIV/AIDS.

The chronic nature of HIV/AIDS takes its toll on caregivers. Family members can get tired of caring for a sick relative as one interviewee showed. Professionals were shown to be insensitive and uncaring in some instances. This could be a manifestation of the stress resulting from daily attending to many patients who have a dreaded disease (HIV/AIDS). In this scenario, it would be interesting to know if there is a programme in place, to take care of the caregivers themselves. If it is there in Botswana, it is either not well publicised or the interviewer was not aware of it.

Thus there is a need for caregiver education and support. This would help care givers to know what they should be doing, and how they should do it. It would also enlighten caregivers on what they should expect to happen to those they care for and to themselves. It will help them to realise when they need support for themselves or for those they care for.

Interviewees did not seem to understand or to accept the criteria for qualifying for government food aid. Thus in some cases they felt that social workers were unfairly denying them this aid even when doctors had recommended it, in some cases. Though government has scrapped food aid to many PLWHA, this problem illustrates the need for transparency and communication in government programmes. It also points to the need for government to involve PLWHA in formulating policies and programmes that affect them. This would help make appropriate and effective programmes that PLWHA could identify with. A word of caution is needed at this juncture. It is the grassroots organisations that have their finger on the pulse of PLWHA. Organisations that deal with papers, in air conditioned rooms, far from the PLWHA, may not be as effective in identifying and dealing with the needs of HIV/AIDS sufferers.

The interviewees' narrations illustrated that taking care of HIV/AIDS sufferers is the responsibility of parents, siblings, friends, NGOs,

churches, social workers, health professionals etc. It is the responsibility of communities and nations as a whole. It should not be the responsibility of one person or a family only. Thus all those involved in caring for PLWHA need to be properly vetted and those who pass the test need all the support necessary to achieve their goal, which should be, a better life for PLWHA.

This study was conducted in an urban context in poor neighbourhoods. Almost all the interviewees were young, poor, unmarried, unemployed folk who had children and other relatives to support. They lived in congested, poor housing, in environments of low hygienic standards.

The interviewees were devastated when they found out that they had HIV/AIDS. No amount of prior counselling seemed to prepare them for such a moment. The realisation that they had HIV/AIDS was accompanied by psychological and emotional torment. It was as if they were plucked from a world they were familiar with and placed in a different place altogether. A new dehumanising status or label imposed itself permanently on them; the label of HIV/AIDS. They suddenly became inferior, undesirable, stigmatised people. This made them develop social phobia and they were in great fear of their HIV status being revealed. Some of them became reclusive and were only comfortable among other PLWHA.

The disease also ravaged their bodies physically and they went through a lot of physical pain and watched as their bodies changed. They were bewildered by all this and did not know what was happening to them.

As their bodies succumbed to the disease, they found that they could no longer work. They lost their jobs and along with this, their means of self-sustenance. They could no longer support themselves, their children and their parents. The interviewees reported the pain of seeing their children go without, when there was nothing they could do to help them. They became impoverished and destitute. They became dependent on other people for their needs and the needs of their dependents. They no longer could eat as well as they used to because they had no money. Their children also suffered lack and this was another worrisome point for them. Though they could source government programs for support, these were unreliable because criteria for eligibility did not seem to be clear or well defined. The interviewees did not want to depend on hand outs. They wished that government could give them jobs or train them for jobs so that they could support themselves.

The interviewees were subjected to stigma and discrimination. This occurred in the work place, in the community and in their homes. This was a painful experience. This made it difficult for interviewees to disclose their status. When they got better, it was difficult to get their jobs back because of stigma and discrimination. Interviewees developed delusions. They thought that people could see that they had HIV/AIDS. They thought that whenever people talked about HIV/AIDS, they were actually talking about them. These delusions tormented them.

When they started ARV treatment, interviewees found that they developed very healthy appetites. However they could not satisfy these

appetites because they had no means to do so. Not all interviewees could access government food aid. This was another area that caused pain for those who felt left out.

HIV/AIDS disrupted relationships. Interviewees lost husbands, partners, workmates and friends. They learnt to look to themselves for companionship and to find solace among other PLWHA and God. Some female interviewees preferred not to fall in love again because of the previous pain of being deserted by a partner.

Friends and relatives could not be relied upon for material and emotional support. Though in some cases they were supportive, some interviewees reported lack of support, stigma and discrimination from friends, relatives and members of the health team.

Thus interviewees revealed that having HIV/AIDS was a very traumatic experience. What made matters worse is that HIV/AIDS turned them into supposedly inferior (because of stigma), unemployed, destitute people, living in humble congested housing, which they shared with their children and other people.

## **CHAPTER 6: CONCLUSION AND RECOMMENDATIONS**

This qualitative study was conducted in Botswana, a country situated in southern Africa, a region with perhaps the highest incidence of HIV/AIDS in the world<sup>4</sup>. The study was conducted in the poorer sections of Gaborone, the capital city of Botswana. The in depth interview method was used. Fifteen interviewees were selected from a hospice, a support group run by PLWHA and from a church. Non-random, sequential sampling was applied. Most of the interviewees were women, and almost all of the interviewees were poor and living in very humble accommodation in neighbourhoods with low hygienic conditions.

Most of the interviewees were poor people who came from the poorer locales of Gaborone. This may have been due to the fact that they were sourced from institutions located in the poorer sections of this city. It may be because HIV/AIDS has infected the poor people more than it has infected the rich. It may be that HIV/AIDS progresses at a faster pace in the poor because of factors like nutrition and sanitation.

The relationship between HIV/AIDS and social class, in Botswana, needs to be investigated. The more we know about the characteristics of the Botswana epidemic the better. This knowledge would help planners to fine tune HIV/AIDS programmes so that they become more relevant to the problems they are supposed to address.

Most of the interviewees in this study were women. This is in keeping with the nature of the epidemic in southern Africa. Some socio cultural practices make women more susceptible to HIV infection than men in this part of the world. These practices need to be eliminated.

Governments and civil society should work towards making women economically independent. In a country like Botswana where most households are woman led, with a woman as a single parent, this idea needs urgent consideration. Education of women is of crucial importance in this regard. It is one of the most valuable tools for uplifting society. Government and civil society should think of ways of keeping girls in school for as long as possible. Bursaries, and scholarships, for girls should be made available. Benefits for parents whose female children stay in school until completion of secondary or tertiary education, should be considered.

Preferential employment of women who are heads of households, who are single parents, and women with similar qualifications as men, would be helpful. This would enable more women to be gainfully employed and not resort to risky behaviour for economic reasons.

Specific education on women's rights within marriage and within society at large would empower women to protect themselves. This would help them to resist risks perpetrated by errant partners. This education should start in primary schools and be taught to boys also, so that children grow up sharing common values on this subject.

Since it is mostly women who are infected with HIV, this raises concern about vertical transmission of HIV from mother to child. Prevention of transmission of HIV from mother to child should continue to be diligently addressed. Compulsory testing of expectant mothers and prophylaxis should be considered. It is not right that a child be born with HIV infection when this could have been prevented.

The study showed that being diagnosed with HIV/AIDS was very traumatic for the interviewees. This experience changed their lives such that they became new persons who had an undesirable and disgusting mark on them; the mark of HIV/AIDS. This unleashed psychological, emotional, social, inter-spousal and psychiatric problems. In spite of the horror of suffering from these problems, there was no systematic institutional health care to assist the interviewees.

HIV/AIDS is a multi-faceted disease. ARV therapy needs to be supplemented with appropriate professional psychological and psychiatric treatment as and when it is needed. The government of Botswana is already overstretched in its efforts to contain the HIV/AIDS epidemic. Resources have to be found or reallocated to cater for this aspect of AIDS disease. Psychiatrists, psychologists, social workers, and support groups need to be involved in HIV/AIDS treatment. ARV therapy should not be the only treatment of HIV/AIDS. PLWHA suffer various kinds of diseases that are not touched by ARV therapy. These diseases need to be treated by appropriate health workers.

Formal structures need to be put in place to address this aspect of HIV/AIDS. These structures would be over and above the services provided by pre and post-test counselling centres.

HIV/AIDS sufferers find great comfort in interacting with other PLWA.

Government and civil society would do well to encourage and support the formation of support groups for HIV/AIDS patients. These support groups should facilitate the meeting together and interaction of PLWHA. Support groups that are led and run by PLWHA should receive special encouragement. These groups would be healing to the PLWHA and they would also be a good source of input into HIV/AIDS policy. This would be in the spirit of "Therisanyo" (consultation), which is one of the cornerstones of Botswana governance. It is PLWHA who know best what their problems are. They should also be trusted with the solutions or at least, their input into HIV/AIDS policy should be actively sought. These groups would also hopefully restore the capacity of PLWHA to love and be loved.

The study showed that the interviewees suffered stigmatisation. The interviewees could not get their jobs back when they were well enough to work. This was because they were not wanted at their former places of work. Though AIDS has affected almost every family in Botswana and AIDS stigma seems to be waning, it is still there. The study showed that it exists in families, in health workers, in workplaces and even among PLWHA themselves. Stigmatisation is a source of great pain and shame for PLWHA. It also negatively impacts disclosure and help seeking behaviour in PLWHA.

Work still needs to continue in fighting HIV/AIDS stigma. One would premise that behaviour is best shaped in children and therefore this work should be extended to primary schools. Children should be taught to accept HIV/AIDS for what it is and not associate it with stigma. Society should continue to be educated about HIV/AIDS. All kinds of promotions, education and advertisements should be used to combat HIV/AIDS stigma. Celebrities, movers and shakers of society should play their part in combating the stigma of AIDS.

Interviewees were discriminated against at the work place by both management and other workers. This contributed to job loss, and moving from one job to another. This also made the workplace unpleasant to interviewees.

There needs to be sensitisation of management and other workers to this issue so that stigma and discrimination can be done away with at the workplace. Trade unions should also be sensitised to this issue so that they can defend the rights of their HIV positive workers effectively. Unions should be encouraged to help create a positive attitude towards HIV positive workers. Parliament needs to be lobbied to enact laws that protect the rights of workers who have HIV/AIDS.

The interviewees also stopped working when they got ill because they could not cope. They became destitute and depended on other people, government and NGOs for food, accommodation, care, transport and other necessities of life. They also depended on such help to support their children.

PLWHA need financial support, accommodation, jobs and support for their children, especially when they are ill. This is yet another area of HIV/AIDS disease which needs to come out of the closet. As government and civil society we need to apply ourselves in this area. Children of jobless PLWHA need food, clothes, money for school fees and transport to school. Families need not find themselves as unwanted guests of unwilling relatives. They should be helped to stay in their homes if they so prefer. They should be helped in the comfort and privacy of their own homes. This means financial resources are needed for rent or mortgage payments, for food and other needs of a sick, jobless PLWHA. The Botswana government and civil society need to source the necessary funds. Our diamonds should indeed be for development and for supporting those who cannot take care of themselves. It is their diamonds too.

The interviewees indicated that they do not want to live on handouts but prefer to work for themselves as soon as they are well enough to do so. They would like to be trained for jobs so that they can support themselves.

The government of Botswana already has a programme in place (Namola Leuba) which kicks in whenever there is a drought. People are given jobs to help sustain themselves during periods of drought. PLWHA who are well enough to work should have a similar programme. It would help them support themselves until they find other means of supporting themselves.



When interviewees started treatment they developed very healthy appetites but suffered hunger because they could not buy food for themselves. The interviewees feel that HIV/AIDS is more virulent and deadly among those who cannot get enough food. Food was a very important factor in the lives of interviewees.

Food is very crucial in AIDS treatment and government should consider making food available to all PLWHA who are jobless or do not have enough resources to feed themselves and their families. Perhaps what the government needs is better storage and monitoring of the food aid, rather than downsizing it. Monitoring and efficiency are very difficult for any civil service and one would think the same holds in Botswana. However food assistance should be available to PLWHA who need it. Many PLWHA say that they are starving since food aid was reduced and given to fewer patients. They also complain that the criteria for getting food aid and their application are not equitable.

The interviewees felt that the media and other sources of information gave very frightening accounts of HIV/AIDS. This was especially the case at the beginning of the epidemic. Thus people did not want to be associated with HIV/AIDS. This negatively impacted disclosure.

Government and civil society need to demystify HIV/AIDS. This disease needs to be portrayed as a deadly disease that can be controlled. It has to be juxtaposed with other deadly diseases like TB, diabetes and malaria so that it can be viewed as one of many other dangerous diseases. Journalists and other media workers should have workshops so that they can be sensitized to writing about HIV/AIDS in a positive, non-alarmist manner. Government should take a leading role in such initiatives by providing funding and facilitators.

In the midst of all this, interviewees trusted God to take care of them. They believed that God could see what they were going through and that somehow or other He would make sense of their entire predicament.

Health workers need to understand that religion and spirituality is a very important coping mechanism for some PLWHA. Thus health workers should respect the religious and spiritual beliefs of their patients. This is not to say that ARV therapy can be sacrificed to accommodate the beliefs of patients but rather to allow these beliefs to compliment ARV therapy. Religious and spiritual groups are already doing great work in the fight against the whole spectrum of AIDS disease. They should be encouraged in what they are doing because government needs all the help it can get in fighting the epidemic. They should also be given financial assistance to do this work if they need it.

Interviewees reported that having HIV/AIDS strained their relationships with their spouses. Some spouses left after they discovered their partners had HIV/AIDS. Relationships with brothers, sisters and other relatives often changed for the worse.



Family members and caregivers of PLWHA need to be educated about HIV/AIDS. They should be counselled and supported also. This is most essential immediately after disclosure or after they discover that their relative has HIV/AIDS. Government and civil society should put in place appropriate programmes for this work.

Thus this study showed that having HIV/AIDS brings with it a plethora of unpleasant experiences. It showed that ARV therapy, an important part of the fight against AIDS, does not address the whole spectrum of suffering caused by HIV/AIDS. It is hoped that this study gives an idea of how the interviewees live and contributes something to the discussion on what can be done to make the lives of PLWHA more pleasant.

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