

Appendix 2: Letter to Permanent Secretary, Ministry of Health.

The Permanent Secretary
Ministry of Health
Gaborone
Botswana

Dear Sir / Madam,

Re: Approval to do research in Home Based Care (HBC) facilities

I am a private medical doctor who has worked in Molepolole for the past twenty two years. I am a Motswana postgraduate student at The University of the Witwatersrand.

I write to ask your permission to do research on “Living with HIV/AIDS in Botswana.” The research will consist of interviewing patients who live in Gaborone and Molepolole. This research is part of my postgraduate work for the degree of Master of Family Medicine. All ethical requirements regarding research on human subjects will be adhered to.

I treat many patients who have HIV/AIDS. I believe that besides the suffering that this disease causes in the body, it also causes pain and suffering in the hearts and minds of patients. I would like to explore how having HIV/AIDS affects the lives of those who suffer from this disease. This will help doctors, nurses and all care givers to address the needs of HIV/AIDS patients in a more holistic manner. I believe with all my heart that medical care, especially care for HIV/AIDS patients should not be limited to giving patients their medications.

The Committee for Research on Human Subjects, at the University of Witwatersrand, has appraised the research proposal and satisfied itself that it is ethically sound.

The results of this research will be made available to you, and it will be as widely disseminated to care givers, as is possible.

Yours faithfully,

Dr. Vincent Setlhare
Box 343
Molepolole
Tel: 5920260. Email: v_setlhare@yahoo.co.uk

Appendix 4: Letter to the Director, Holy Cross Hospice.

09/05/06

The Director,
Holly Cross Hospice,
Bontleng, Gaborone.

Dear Madam,

Re: **Research in People Living with HIV/AIDS**

Our conversation by telephone refers. I write to ask for permission to do research at your institution. I am basically trying to find out how HIV/AIDS affects those suffering from it. This research is for the degree of Master of Family Medicine at the University of Witwatersrand.

My protocol outlines what my research is about. Copies of permission to do this research (from my university and from the Ministry of Health) are enclosed.

I am a Motswana and I look forward to interviewing your patients.

Yours faithfully,

Dr. Vincent Setlhare

Appendix 5: Letter indicating contents of pre interview explanation to interviewees.

Dear Patient,

Re: Living with HIV/AIDS in Botswana: The experiences of some people suffering from HIV/Aids.

I am a private medical doctor working in Molepolole. I am a Motswana and I am doing postgraduate studies at The University of the Witwatersrand. I am doing research to explore the effects of having HIV/AIDS. This is part of my degree work.

I treat many patients who have HIV/AIDS. I would like to find out what people with HIV/AIDS go through in their day to day lives. I would like to find out how having HIV/AIDS affects your life.

You can help by telling me about your life after you knew you had HIV/AIDS. Your name is not going to appear anywhere after you have told me all that you want to tell me. You are not going to be asked to identify anybody by name. All I am interested in is your feelings, thoughts and experiences. The whole exercise should take about fifty minutes. If you do not feel like talking about these things, please say so and you will not be made to suffer in any way. If you agree to participate in this exercise, please feel free to stop whenever you feel like you cannot continue.

I will give you my phone numbers and address so that you may contact me if you get into any problems in connection with this research.

Thank you for your time and assistance.

Yours faithfully,

Dr. Vincent Setlhare
Box 343 Molepolole

My clinic is in Molepolole, in the Mokgalo ward, opposite the Community Centre.

Telephone: 5920260 or 71549304

Appendix 6: Sample of questions used to collect demographic data.

VS – Who is madam?

A7 – I am N. U.

VS – N. U.

A7 – Yes.

VS – How old are you?

A7 – Thirty five.

VS – Thirty five?

A7 – Yes.

VS – Are you married or not?

A7 – I was married then my old man (husband) died.

VS – He died?

A7 – Yes.

VS – When did he die?

A7 – In 2003.

VS – 2003.

A7 – Yes.

VS – Do you have children or not?

A7 – I have two children who are boys.

VS – Ok. Are you working or not?

A7 – I do not work.

VS – Ok. Did you work before or not?

A7 – I used to be a seller of chicken intestines after he (my husband) died. Then I was taken out (of this job) by illness.

VS – You were taken out (of this job) by illness?

A7 – Yes.

VS – Where do you stay?

A7 – At Old Naledi.

VS – At Old Naledi. Ok. Whom do you stay with at Old Naledi?

A7 – I stay with my children.

VS – In your own place?

A7 – No. I am renting.

VS – You are renting.

A7 – Yes.

VS – Ok. How many rooms are you renting?

A7 – One room.

VS – You stay with your children and who else?

A7 – With the child who was nursing me, my sister's child.

VS – Eh heh. You're four.

A7 – Yes. There are four of us staying in this room.

VS – This other girl is she working or not?

A7 – She does not work. You see, she came from my home village to nurse me when I was ill, I was alone because the children I was staying with go to school.

Appendix 7: What the interviewees said: Thematically categorised.

Psycho-emotional matters.

A1. When I went to sleep at night, it would be like I am mad. I did not know what was happening to me. I felt like running away. I felt like running away so things like this make one talk by ones heart (think a lot) It makes me talk by heart. You see I did not think my illness would take so long Now I have accepted myself (I am at peace with myself), at first I hurt a lot. My heart was always painful, 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. Then I started accepting myself well, telling myself that I will get well. In the beginning I used to hurt a lot. 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, telling myself that I was going to die. Now I am alright. So you have to comfort/console yourself. Ifin this world you came alone. It is just that I just comforted myselfcomforted myself.

A2 As for me I do not have parents at all. My parents have been lacked (are late). I am the last child of my parents. When I talk about my nephew. No it is painful that when I talk about my nephew, who knows that I am his unclenot knowing that if I am running short in the house, then he does not know that he should help me. Like now I have not yet told the problems that I have ... to my sister. They laugh when they see us eating these pills they say that I am ill etc. etc. I must go and sleep and listen to myself (rest) because I am ill. Then I wonder, if someone is ill should that person be sleeping all the time? Yes, they are able to speak in public, not mentioning what I am suffering from. They tell me that I am ill only, not explaining what I am suffering from. This shows that this person can tell somebody what I am suffering from.

A3 I just accepted my fate because I got into the ante-natal programme. I live by begging, such that I do not stay well with a good heartwhen a patient hides himself, sometimes it is because he does not want people to know his illness. He just keeps quiet. Not telling anybody until people realise when he is very ill. He had been hiding the fact that he is ill. I was just telling myself that I am not living well, not knowing what was happeningspending the day alone and again I could not cook for myself. Now when the hospice people entered my life....When the hospice entered No it became better, even if I am here I do not have a problem. I spend the day with others. When I leave, I go home. The following day we come back etc. Now I live well.

A4 Sometimes when I ask a person (the young people) to make me porridge, they refuse. They tell me that they are tired and nothing can be done. Now such a life is very difficult. I am a person that has lost parents. My younger and elder siblings are dead. I am the only one left of my family, you see like this. Now I never get troubled. Even if somebody hurts me, I do not have time for him. I only look at the fact that when someone does that, he knows what he is doing. Mine is just to get out of him (ignore him / leave him) and then take care. I never provoke another person. When they make fun of me or scold me, I just tell myself God is there. What they do to me is like refusing to wash for me.

A6 I just felt that Ah! I am not the only one in the country. I am not a strange phenomenon. What has happened has happened. I accept the disease. I accept myself. It is alright. I accepted myself and put myself before the Father of Lights (God). The Father of Lights knows each and everything. He is the Judge and there's no one else who knows anything except Him alone. He is the one who shall cure this disease at the time He cures it. The people at St John's Church told me that I should pray a lot. They say I should pray earnestly I should pray a lot. Even at the hospital they used to go and pray for me at the hospital. In this life that I live I only say no, it is all right, I have accepted this life. There's nothing I can do. When this kind of life has arrived, it has arrived. I have accepted this life in my heart.

A7 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. I just stayed put until now, in 2005 when I got ill. I don't know but before people used to say that if you take treatment you die etc etc. So we were still backward, afraid. Now, at present, we have seen that life, when you start treatment, and use treatment properly, you are able to get well. 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. Tomorrow 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 alright. I think a lot and find that my heart is not all right. Because children tomorrow come with this report, they want money from me. Now me, I don't have money. This is the thing that troubles me a lot because I was not my children are not used to going without (being paupers).

A8 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. If they came at all it was not like Here we are nursing a sick person. You see when you are sick and your heart is always feeling pain, it is not easy for you to get well. They had left me with their children I found myself accepting my fate.... the thing that hurt me the most was even buying food, they were unable. It's like they were not able to do anything for me.

A10 You know, I have at times shed tears.... because I strongly wish I was working now. I just took it that you know if an illness has got into you it has got in. There's nothing you can still say. My life is not pleasant in

the way I am ill because there's nothing I can do for myself. It is not pleasing to me because I don't like to be like this. 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. Then it means that I get out from their midst so that I can take my heart out of such things and say to myselfwell 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 memy 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.about my life I don't understand how I am. I am not at peace with staying the way I am staying (the way I am) in the state I am in.

A11 (laughs) Me, I feel alright. There's no change at all. Me and other people, they do not know what my illness was. Up to now they do not know what my illness was. I take it that is my secret. It is my secret. Like your side (you have secrets). 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. Like I used to go to discos. Now I watch TV after that I sleep. The next day I do the same. I don't go anywhere. If I am bored by TV I go take a novel, go to the bedroom and read. .

A12 The only thing that happens is the anxiety (being afraid) because people always say it's being afraid that it is obvious I am going to die because I have the HIV germ. This is the thing that scares me a lot. You see people say that this illness is a killer. People say it is a killer. That is the thing that scares me. Even in the media we read that this is a dangerous illness. They talk a lot about HIV/AIDS as being a dangerous enemy, a big dangerous enemy. I want to live like a person who has no germ altogether even though I have it now. My goals are not fading, my dreams are not fading because I have HIV/AIDS....hey, I lost weight. 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 That I was as good as dead 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. Now it is found that I have the germ and people are saying it kills It means I am going to die too. 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. I believe that God will give me strength to find what I am looking for. I also believe that I should be self reliant That I should work That I should work. I don't have a career but I do any work, only work that is available. I am over burdened with problems but nobody is taking this burden off me..... we people with HIV, if you compare us with people, you would think that we are not people.

A13 Also stress and talking a lot in my heart (anxiety) because of the way I was treated by my friends and my younger siblings. I went for counseling a lot.... 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. 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. 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). I would take it that when they talk about HIV it was about me alone. I really had a problem. I would take it that when they talk about HIV it was about me alone. I really had a problem. 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. Even when I am relaxed with people, I can take my pills. I am free and I am ok now, nothing happens.

A14 It means that I did not accept my status. It so happened that if I was among people I felt as if they annoyed me you see. Then I ended up seeing that well, I can't cope and I better go and stay at home. The only problem was myself. 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. My mind was occupied with the illness.... like, "when am I going to die etc." They are not able to live relaxed lives knowing that they are people and are alive. They have given up hope. This is lack of accepting oneself, this leads to giving up hope and just staying at home, and telling oneself that this is the end. 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. Being despised (by other people) also has its partthe 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",

Because at the end of the day, I know that if I say that by the way my friends I am sick, people say "hey you are dying". Sometimes even if always I know that when I meet Tshidi I ask for water and she draws water and gives me, on that day when I get to her and ask for water, I ask myself if she will draw water for me or she will see that I am sick, or should I just not ask for the water. You see I am in a confused state. I am not able to be my natural self. I have now changed somehow and I tell myself that this person must be noticing (that I Am ill).

A15. Also 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 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. Such that 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. I did not listen to me, and I did not feel well. Even friends, there's no friend I told. 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 painand sleeping all the time. It was not because my body was painful, no. It was just that I had stress. Now since I met with people of this organization, we spend time together, chatting and visiting ill people. So I discovered that hey! I am not the only one who is ill. That's why sometimes you see us getting very ill. It's 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).

A16if you cannot accept yourself, nobody can accept you. – Mm, my brother! You see like just now, when we tell people to test (for HIV), somebody will say "I have been counseled, 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 knowto me it was like I was leaving one world/country and I was entering another world/country. Even if you have been counseled, but if you are told that you are positive, thoughts comewhen 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, because when it started, HIV was thought be due to the person having been a prostitute promiscuous, etc. So you have to deal with all these things to begin with. The day I was told I had the germ, I did not even believe it. HIV requires that you should be at ease in your spirit, living well. Yes sir the main problems in our lives are shelter, joy..... we know the pain of this disease.

A17 Hey! Really I accepted myself. I accepted my life. I accepted the germ. 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. I have children. My children are three. All of them depend on me. 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". That's the thing I thought about mostly. I thought a lot about my children.

Relationships:

A1 Yes, the people at work used to visit me and tell me that they would look for a suitable job for me. Now these days I think, seeing that I I have taken a long time without getting well they do not phone. I would say since I got ill, friends get out of you (you lose friends). Friends leave and you start leaving your life alone. They (friends) get themselves out of

you. They (friends) get themselves out of you. So you have to comfort/console yourself. Ifin this world you came alone.

A2 When you deal with a person who is a nephew it does not mean he will work you (work for you), he will sooner or later say, "What is wrong with this guy, he is pretending to be weak (deliberately over dependent). He must do for himself (fend for himself)." He is concerned about himself only.

As for me, honestly he is far away from me. No he is completely unable (useless). He is refusing. He says has children. He says that he has children. You see when someone says this to you he means that you must get away from him and not make your heart painful. It means you must get out of him and see in what way you can live.... 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).

A3 These are the things I have been discussing with my mother (that I want to meet with the, social workers). She tells me that it is not possible (to go and stay alone) because if you are with your parents they look after you at home I am really well taken care of.

A4 The child's mother is there but we are not together. 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. . 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. When they have something (money) they throw it at me.

A6 We at home really, we have a difficult life but we are in good terms (we hear each other).

A7 respondent did not mention anything in this area

A8 At home I stayed with They (her sisters) had left me with their children, but it is a small child of 1986. It is just now that they are showing love, that no here is a person (herself) etc etc. You see, they should have shown this love when my illness started you see. They stayed away just like that.

A10 Really I don't know how I can tell you that I live pleasantly because really even peopleah! There are people who look at me and are able to say to me whylaughing at me in the way they heard about this illness that is holding me. Now it means that at times it does not make me eat nice things (it is not pleasing to me) Then at times it means that I feel like keeping to myself staying alone there (in seclusion) so that I don't mix with them because you know that such people it means that they are not able to love me.

VSNo you said there's a lady whom you live with or whom you lived with (girlfriend).

A10It is some lady, the very one whom I thinkcould she be the one of this illness or not? But I have not told her anything. 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).

A11 VS – You talked about the lady you were in love with.

A11 – Yes.

VS – How is it?

A11– Like. As for now, we are out of touchbecause she has found another lover.

A12 Even friends nothing has changed. They are still my friends.

A13 All things became spoilt, even the father of my children left.

VS – He left?

A13 – Let me say he went away. I mean he left at that time. Really when I started getting ill, and my illness got obvious I found that there was not even one friend who accepted me. I was accepted by the parent who breastfed me. Even my siblings, they did not treat me like I was the child of their mother. . I called the most senior one, she is here, and I told her I was able to talk to her a lot when I was ill and then she said When she spoke, I saw that she spoke with a sorrowful heart. They all changed against me. It's just now that they are coming back because they see I am well. I used to have friends. They would come to me and say, "Hey what are you suffering from? How come your TB does not get cured?" They got satisfied or gave up when I told them that I had the germ. Then it became better because they stopped asking questions... All people including friends and my boyfriend, it's only now that they see that I am a human being.

A14 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. Like me I befriend other people like I am in this support group.

A15 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. The father of my first child he stays in Broadhurst. He just left me and went away. He stays with another woman.

A15 – I told him that I have "the germ".

VS – Then he deserted you?

A15 – Hey! He proceeded to other places (he left). So from then onwards I took the idea of having a man out of my mind. That is I do not want to have a friend (male friend). My only friend is God.

A16 VS – Ok, your husbandyou are married isn't it?

A16 – Yes I am married. I met Mr M in 2002. Mr M met me when I was HIV positive and he is negative and even now, he is negative.

A17 I told myself that really, as for sex, I would quit having sex completely. Now since I started living with the disease, I quit sex Up to now But reallyI have no problem. I am all right. I told my mother. My mother accepted me and I also told my brothers, they also Really they helped memy friendsmostly they are Christians. The children of God have not shown me bad behavior. They used to come and visit me as children of God.

VS – The gentleman you live with (boyfriend) how did he take you.

A17 – Hey! The man I was living with, just when I started getting ill before I tested, he leftI think he left because of the fact that he saw that I was ill.

Stigma:

A1 Interviewee did not say anything concerning this subject.

A2 They laugh when they see us eating these pills. ... sometimes I hear, some people teasing me / provoking me with some words. Then I become aware that I must not complain and I leave it at that. I am sick by myself. No they say that I am ill etc. etc. I must go and sleep and listen to myself (rest) because I am ill. Then I wonder, if someone is ill should that person be sleeping all the time?

A3 You see if you look, some people hide ill people in rooms. They hide them in rooms – not wanting people to see them..... There are patients who hide themselves... when a patient hides himself, sometimes it is because he does not want people to know his illness. He just keeps quiet. Not telling anybody until people realise when he is very ill.

A4 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. I do not know whether I am dirty and nauseating to them or not. When they make fun of me or scold me, I just tell myself God is there.

A6 Interviewee did not say anything concerning this subject.

A7 Interviewee did not say anything concerning this subject.

A8 I was asking myself, "Really, my sisters, why were they not visiting me?" 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.... I noticed some people like to discriminate against other people. You see how it is. When a person is said to have "the germ", another person when he looks at himself, maybe this person having "the germ" but without knowing it; when this person hears that K has the germ, he will then tell himself that hey, K ... it means it would be desirable that she should not stay with us.

A10 There are people who look at me and are able to say to me whylaughing at me in the way they heard about this illness that is holding me. 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.

A11 Up to now they do not know what my illness was. I take it that is my secret. I have not yet come to a stage where I can talk openly, telling somebody (about my illness). I feel that maybe people can become afraid of me / shun me or something, you see. I feel I would lose my friends.

A12 The thing is I don't tell each and everybody that I have the germ. Because some people don't know how to handle thingswhen you tell them, some take you lightly. They take your health status and spread it such that everybody knows, even when there's no need to do so in some work places, 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.

A13 Really when I started getting ill, and my illness got obvious I found that there was not even one friend who accepted me. I was accepted by the parent who breastfed me. Even my siblings, they did not treat me like I was the child of their mother. 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 But as time went on They would just call the child and ask the child to give them the food and put the food away. And then send the child on a false errand just to make the child not to eat what I had given the child and give the child something else. They shunned me. Even if somebody had a cup in his hand, if I asked for water, I noticed that he had problems to give me water really

A14 People still think that if they enter through this gate people will say "You see him It means that he is inside (he has the germ)". The main big thing that makes people not to live like other people is because of giving up hope. It is the stigma. It is looking down upon oneself. It is stigma and discrimination. You see you despise yourselfLike she says when she started telling her younger sisters, it was like even when she handled a cup, they would break it. If she handles a plate It was like "she should not handle anything, she is ill". If she handles that bottle you are carrying, she will infect you. If she handles a piece of cloth it will not be used again.

A15 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. They talked about it like if you have this illness it means you were a prostitute. 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. But I have since noticed that it does not infect prostitutes only. Once you tell them that you have “the germ” if you can’t keep it secret if you tell them you have the germ, you know how a person is. Yes. You see they will start to be nauseated by me and not taking me as a human being. Then they will say “Ah? Ah! Go away lady. You mean you can come to work for me when you are HIV positive. You will to infect me”. . The thing is people take the germ asa big sin...

A16 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)’. You see when I say stigma or discrimination, at that time in 2002, HIV/AIDS was associated with certain people. You see, it was not for me that I am HIV positive. It was that if you are HIV positive you are a prostitute, or something. Stigma is a scar that makes you say “What shall I do? Will people say, I have the germ? I am not going to access government programmes because”...

A17 These days, when you have been ill, they take it thatit is likeeven if you have not disclosed your status to them they assume that you have the germ. I mean... people...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..... during the time that they see that you are ill, you’re still ill, people don’t treat you well.... really even other patients....its 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.... they are nauseated by them. They do not treat them well. It’s like they think that if you are living with the germ, if we use the same cup, to drink water, they take it that you will infect them with the illness (HIV/AIDS).my younger sister who died, she had the germ, but she had not yet tested (for HIV). She had a small child. Even her child had the germ. It is like my other younger sisters at home, they used tolike this childthey used to say she should not eat with others and should not use the same utensils as other people. Her utensils were hers alone and she should eat alone.

Life after stopping to work:

A1 Now things have started to be difficult. It is not like before when my disease started. In the beginning my elder siblings used to help a lot with everything I needed. Now when they saw that I was getting better, they retreated (stop helping me). It means I am looking (depend) at this one with whom I stay at home. Life went backwards because even the things I had thought of doing were stopped because I could not work. Now it means that I beg. I can no longer do things for myself. So it is still...it is difficult honestly.

A2This illness is oppressing us a great dealsuch that, just now, the way it is like I am not working, I lack a lot of things. Like eating, I do not know where I will get food There's nothing I can do for myself. It is not nice to be given all the time. It means one should think for himselfone accepts things because there is nothing one can do for himself.

A3 No, since I got ill I see my life has gone back. I can't do anything for myself. Even when I go to hospital I cry to my parents (beg for help). Yes I say it has gone backwards because, I used to hold with my hands (work). Now at present, I live by begging, such that I do not stay well with a good heart.

A4 Now, the life I lead is a very lean life (difficult life). We do not live well because, the old lady (aunt) is the only one working. She does everything, like the house She pays for the plot, water, electricity, etc. She buys food. Nobody is helping her,... 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. Now me I save, so that if nothing is cooked I can buy something to eat.

A6 Just now at home we lead a very difficult life because sometimes we only get money at month end, to buy food like now when there is no food. Like now, as I speak to you, we do not even have paraffin. I do not know what we are going to use to cook porridge this evening, when we sleep. There's no paraffin, there's no money. There's no one who helps us.

A7 Since I got ill, my life has gone down.... I have a younger sibling who stays at Tsolamosese (Take off your dress – a township). She is the one who works. Now she is the one who helps us by paying our rent. I used to be able to do for myself (fend for myself) since the death of my old man. I sold things and was able to support my children. Whatever they needed I could help them with it, now these days there's nothing I can help them with. . Our problems which I want doctors to know is that if we can be helped if you are not living well. With social workers to help the children when you are ill because these days they pay at school. They should not come to you for money because they know that you are ill.

A8 In fact she (the cousin) is the one who said she wants me to visit her. It was that after two weeks I would go back. So after staying there for a week I saw that I was feeling good about the place more than at home. So I told her "How would it be if I came to stay with you? Is it not that it doesn't matter and you are not inconvenienced in any way?" Because I had told her that I have an illness and I am ill like this and this. She said, "No, me I don't have a problem with you. Just stay. I am working there's no problem. Whatever you need I will do it for you."

A10 The old lady is the one who is renting out rooms, she is the one who is helping me with the maize meal which we eat together with the children at home. When I got ill like this, my life stopped because really there's nothing I do for my self (can't support my self)my life is at a very low

level. It is not like the time before I got ill. I was able to do everything for myself. Like clothes, I was able to buy myself clothes but now I cannot. Now I see that all my things have stopped. I just suffer on my own like you see us coming here (to the hospice). These ladies of here, haisometimes, some white ladies sometimes bring torn clothes (old clothes) and they give to usmy life is behind a lot

A11 The half salary does not satisfy me. Like I used to have a full salary... it cannot get me some of the things I need in life.

A12. my life has not changed because at the time I went for testing I was not working at all. . The disease is very bad for people who are not able to help themselves, those who have nothing. To them it is very bad you find that even the body of the person changes all the time. It changes The weight is not alright etc, etc Because he cannot get He cannot get everything he needs. He cannot eat what he needs, he cannot get what he needs timeously. He is always in lack of everything. The help I need is work, food, where I sleep, these are the things I need in life. Others like a good future, I can do them for myself, if I can stop worrying about what I will eat, what I will wear.

A13 All things became spoilt even the father of my children left. These two rooms that are being let are our income. Sometimes I get a piece job to go and do washing for somebody. What we lack is glycerin. We live together here in this home (we share whatever is there). When somebody asks me to do washing for him and they pay me, I go and buy what we lack. The following day one of us gets something and buys what we lack. This is how we live. The social workers took my name. I don't remember when. This is the third month that I am getting free food. They say this arrangement is temporary, it's for six months.

A14 This is my parents place....there are rooms which are let out to people; about seven. I am a dressmaker..... if a person wants something and they say "please sew this for me", I take and sew knowing that I will get money for bread. But also sometimes when I have money, I I am a person who likes to go to South Africa. So when I have something and I see that this can enable me to buy such and such, I run to buy stuff to sell here. That is how we survive.

A15 I pay rent by doing piece jobs. Hey! It is heavy (very difficult). It is not like before I got ill. Before I got ill, life was likelife was much better. I was not suffering much because I was taking care of my children and I was taking care of my mother. I was workingI can't cope. I can't cope to such an extent that even today I went to the sister (staff nurse in charge) at the community (clinic) to ask for a uniform for my child and school fees because I cannot pay P300. Hey we are not coping (sighing). I sometimes remain with her baby when she goes to do some washing somewhere. Then she comes back. Some other days when she is not feeling so well, I go to look for washing jobs. Then I come back. But its not that we get these jobs everyday. It's at odd times (that we get them).

A16 VS – These other rooms are yours and you are letting them out?

A16 – Yes sirMy husband is working.

A17 One of my brothers he said he would pay for my rent, until I get well. He did as he promised and continued to pay for my house for a year and six months-he was giving me two hundred pula for rent until I was well. My child was attending school in Ramotswa (30km away)....My brother continued to help me by giving him money to go to school every morning. My life has been affected because I am not working.my children....sometimes they need something at school. There's nothing I can do. Really I can't manage. I live by struggle only. Sometimes I ask for helplike the pastor and othersthey help me,.....but really I can't manageNow here, when I try to ask for (government) assistance from social workers, they tell me that I should go and ask for help in my home village. Now....reallylife is tough.

Concern about children:

A1 I mean like sometimes when something is required of my children at school, they think thatthey now trouble me because they remember that they never had a problem getting these things. They want money for “dress to kill” (at school) when there is no money. 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.

A2 I have even abandoned my children. Even the children's relatives want to see what I can do with the children (take responsibility) I must know what I can do with the children. Messages come every now and then,I have one year without going to check on the children. My children also go hungry, there is no way I can work for them on any day.... so it means it is just problems.

A3 This female participant did not mention anything concerning this topic. She has two children.

A4 This male participant did not mention anything on this topic. He has one child.

A6 This female participant did not contribute anything in this area. She has no children.

A7because I have children who go to schools. “There's nobody who helps them,” I said a few days ago in March, telling the nurses, because there was nothing we were we eating. Now it means uniform is a problem at school. If something is needed at school you find that You see a child does not know that you are ill or you have a problem. The child, when he gets home just brings a report that this and this is needed at school and you won't know what to doI sold things and was able to support my children. Whatever they needed I could help them with it, now these days there's nothing I can help them with. Even if they want money for nice clothes, I am able not to have the money, there being nowhere I

can find money.... With social workersto help the children when you are ill because these days they pay at school. 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.

A8 This female participant did not say anything on this topic. She has no children.

A10 This male participant did not say anything on this topic. He does not have children.

A11 This male participant did not contribute anything on this topic. He has one child.

A12 This male participant did not contribute anything on this topic. He most probably does not have a child that he knows of. He has no steady girlfriend.

A13 This female participant did not contribute anything in this area. She has four children.

A14 This female participant did not say anything on this topic. She has three children.

A15 Like after leaving work, when my child was going to school, I had no The child has no uniform and I had no money to buy him uniform. 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). Like a few days ago when I told the sister (clinic nurse) that my child's shoes had holes, the sister said, "Ah! Here we help to pay for children's school fees". I felt my heart become very painful (I was very sad) you know. Then my child came to Gaborone. I told him, "my child, wait a bit so that I can find a piece job and then buy you some shoes". Eh. It is really difficult since I stopped working.

A16 This female participant did not say anything on this topic. She has one child.

A17 I thought about my children. I have children. My children are three. All of them depend on me. 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". That's the thing I thought about mostly. I thought a lot about my children.

Food:

A1 Now I can eat, it is not like before. I feel like eating frequently. The pills make me want to eat because if I have not eaten, I shiver. Eh...Such things...Because when you take them, you want to have eaten something

otherwise you won't feel well. When you take them again they (the pills) eat the food you had eaten before and make you want to eat again.

A2 Like eating, I do not know where I will get food.... The thing which is a real bother, the thing that really bothers me, it wants food (the need for food). Like they say we should eat vegetables, you see things like beetroot...that one can grow these for oneself so that one can have blood in the body. I live by eating here (at the hospice). You know, like the weekend is entering. I know that as the weekend is entering, Wai! (exclamation of despair) it means I just stay with hunger. It means I should stay under the health team's surveillance / treatment. There's nothing I can do for myself. It means I should stay under them so that I can be treated properly, eating certain kinds of foods ? fruits and vegetables? Now during weekends I cannot get them.

A3 As for food I don't have much of a problem because I am given food at the council (Gaborone City Council).

A4now you'll find that when it comes to eating, we eat once a day. We eat in the evening only after the old lady has knocked off. Sometimes we don't eat at all. Now I am only helped by coming to the hospice so that I can eat better food. Spending the day here, you see, I do not suffer hunger.

A6 Even now they (social workers) say I should not go to them. I should wait for them but our food is getting finished. Now the pills I take (ARVs), they are strong and make you eat. The main problem is food. Accommodation is alright. We struggle with food and paraffin.

A7because there was nothing we were we eating. 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 in the month that has just ended.

A8 You see the thing that hurt me the most was even buying food, they were unable.

A10 As for eating, I eat well. The problem is clothes (the lack of them)

A11 This participant did not mention food.

A12 Food, clothing and food, these are the things I need a lot. The main needs are food etc.

A13 If they can help us with food and also find us jobs, it will be goodthey (social workers) say, doctors should not help us with food, because it is the responsibility of social workers. They say if a doctor writes down what you should eat, he means that you should go and buy it. That is what they tell us. They got me into the food program telling me "we are giving you food on a temporary basis".

A14 People who are taking ARVS (anti retroviral drugs) I myself have not started taking them, the way they talk about them (ARVS) they are things that really all pills including those of HIV, all pills when you take them, they are things that require that you should have eaten something. Really the people with this illness they needthey wantwhat should I say a balanced diet, for them to survive. Because pills should be used with food.

A15 VS – What about food?

A15 – Hey! That’s a problem area. It’s a problemthe saving grace is that hunger does not kill. Maybe we would have long died. 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 tobecause 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, they have no food

A16 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. Because when you have “the germ”, it eats, from the (infected) person. And the virus wants a person to eat well, live well, sleep in a nice place, and the heart (of the infected) should stay happy. But because of the stress of life, because of food (the lack of it) we are dying.

A17food runs out in our home.

Work:

A1 I used to work. I used to work in a shop at the university. I was taken out of my job by my lack of good health. I am praying that I should get well....get well and look for a job so that if those(previous employers) do not accept me....look for a job and work and start life afresh again (long pause)

A2 I am not working. I separated with work in 1999. I was ill. Mostly, people come and say that they beg me to do something for them....like building a toilet for them. Now these are jobs one gets after a long while.....things like “build me a toilet I’ll give you three hundred pula”so that one can buy oneself some food. Now if there is no job there is nothing. Like now there is nothing I have. My children also go hungry, there is no way I can work for them on any day ... so it means it is just problems. There’s no way that someday I can work for them

A3 I am not workingI used to work at Kitso ga e golewe. (One does not grow too old to learn). 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. I was not able to do anything. I then asked that somebody hold the job for me. So I asked them to let my younger sister to come and work in my place

A4 I do not work. I left the job because of ill health.

A6 No sir I am not working. I used to work and then the disease took me out of work.

A7 I do not work. I used to be a seller of chicken intestines after he (my husband) died. Then I was taken out (of this job) by illness.

A8 I don't work. I was a person who used to get part-time jobs; temporary jobs. The temporary job got finished. I want to take the treatment (ARVs). I get them from hospital well (as prescribed), so that I can so that I can start working. This will make life (health) come closer and become longer in me....

A10 I worked before I got ill. I was taken out by this illness because I was feeling that my body was not able to make me work well the body is ill and light such that even work, I don't see that I can work; maybe work that is not heavy like when somebody says, "Do a little something for me", so that I can get a little something a little five pula (Botswana currency = R5) I have at times shed tearsbecause I strongly wish I was working....

A11 I work. I am a policeman, by work.

VS – Have you already started working or not?

A11– No I haven't started yet.

VS – So you have been out of work for two and a half years.

A11– It is like that (long pause, A11 laughs). Now sometimes I find myself longing for work...

A12 VS – Now that there are eight of you, how many are working?

A12 – No one is working. I am the only one who sometimes works. Yes I am working but my work has been spoiled (it has ended). The problem is they were paying me at a low rate.... they got annoyed and said I had taken them to court. They then asked me to leave work (they sacked me). Sometimes at work these days, if you reveal your status, you end up losing your job. The help I need is work...

A13 I am not working. In 2004 I started getting ill but in my illness... I could not cope. Even when I went (to work) I could not manage. I have not gone back to them. I have got better only recently. Sometimes I get a piece job to go and do washing for somebody. If they can help us with food and also find us jobs, it will be good. Those who feel well, we would work for ourselves and earn some money... if we can find a place where we can work, we could be able to do something for ourselves and support ourselves.

A14 I used to work. I used to work I stopped working in 2002. After I checked myself (for HIV), it means that I did not accept my status and it so happened that if I was among people I felt as if they annoyed me you see. Then I ended up seeing that well, I can't cope and I better go and stay at home.

A15 I am not working. I used to work. Because of ill health I stopped working because I was no longer coping. Now I feel better, I can cope. Sometimes I go to market myself (job hunting)... sometimes I can't even find piece jobs. . I wish I could get a job. This is the help that would satisfy me. Because in my life really I believe mainly in having a job working for myself.... my desire is that I should work with my hands (be self employed); not depending on anybody.

A16 – No I am not working. My husband is working.....

VS – In other words you are saying jobs are being taken from PLWHA to people who don't need them as much.

A16 – (Affirmative) where the jobs are not needed. ...government says it is empowering people living with HIV and AIDS, which is not true.

A17 I am not working really.... I live by getting piece jobs. I could not continue working because of illness Then I left my job. I left it because of illness. Where I thought I was where I used to workI went to them to ask for a job. They refuse to employ me now... it is like.....even if you have not disclosed your status to them they assume that you have the germ. I meanpeopleif someone is living with the germ, it is not common that they can hire him... after you get ill....you can't find a job there are councilsthey should look for jobs for us so that we can be trained". They say they are not able to find jobs for us.

The disease- HIV/AIDS:

A1 I started feeling very cold, at work. Then I thought that maybe the area I was working in was coldThen I moved to another side because dizziness and fevermy temperature would be about 38.5 (centigrade). One time I went to work in the morning, wearing many layers of clothing. I was shivering in spite of this. My temperature continued to rise.

When we got to Tebelopele I was checked and it was found that "the germ" had got into meThen it started that when I went to sleep at night, it would be like I am mad. I did not know what was happening to me. I felt like running away When I got to the hospital I was admitted. When I woke up I found myself tied to the bed. I did not know what was happening. After I started taking these pills, my feet startedwhen I tried to stand up I would fall down. I had to be supported to go to the toilet. I had to be supported to the toilet. At the end my legs cramped and curled up. I did not know what was happening. My knees were no longer working. The left knee use to like come out of me (easily give). My fingers became bent. It thus became a problem such that I could not walk until today. I had already been put on anti TB drugs also. But when I reduced anti TB drugs (the pills), I saw that things got better because the pain stays in the feet mostly.

A2 I know that I will get well. Eh. As you see that I am already taking "drugs that take the sting out of the disease"(ARVs), I will get wellthis illness isisit is a germ, let me say it is a germ. It can be

treated. The treatment is to reduce the sharpness (virility) it does not mean that the disease kills. The disease only kills if by the time you get treatment you are already very lowI have just started on the treatment. I do not know whether in the end I will be strong and healthy like before, or it will increase my days

A3because 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. What is necessary is that as soon as you feel ill you should seek help. If possible you should go and check yourself (test for HIV) and come and tell your parents the truth. In this way you can live a long time. Like me I was really ill. Now I see that I am a person. I can wash for myself and even my children I wash for them. I can even cook for them. I started having sores. I first I started having herpes zoster and then it healed. After I gave birth to this child, the one who's been passing here, things changed and I felt unwell. I was getting sores and going for treatment / bandagingin 2003. I started ARV treatment. But now I see that I am now better than when I came here. I can do something with my hands at home.

A4 My doctor was very pleased. My CD₄ has increased and my weight has increased also. He was happy with this.

A6 Let me say since I got ill, I got ill and was really sufferingsuffering, not even able to walk. I was admitted in hospital and stayed in hospital and then I was discharged. . It started like when I ate, I would vomit. I was nauseous, not eating anything. When I ate, I vomited; when I ate I vomited. At the hospital they caught ... 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. The lady who stays in our home then comes to massage me. Now when she massages me, it becomes very painful as if there is a wound ... like I could not get up, could not walk, my toes curled up like this... not speaking, with my teeth tightly clenched together feeding me with a tube very thin porridge... breathing oxygen. I should have died then.

My joints were broken (I was weak). It was like when I looked, I would be dizzy; dizziness would come and cover me. Now when the dizziness came, I was able to fall.

As long as you continue your lullers (ARVT), 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. You take them only (ARVT). No you can be alright and you won't notice that we are ill.

A7 I am still unable (or weak).

A8 Because I was taking TB treatment, I was having pain in my legs – they were swelling and I could not walk, I could not do anything for

myself. When my feet started swelling I became unable to come here regularly. I just stayed at home lying down.... I had lost weight...

A10 I was feeling that my body was not able to make me work well. I ended up going to test myself because I said "Why am I moving about with my body not making a person happy (not feeling well)?" I ended up going to test myself and then-----they caught illness (HIV/AIDS) in me and I said, there is nothing that I can say because I am suffering... the body is ill and light such that even work, I don't see that I can work.

A11 I was admitted at Princess Marina Hospital. I stayed three months at this hospital. Then I went for physiotherapy in Francistown until I was able to walkwalk well.

A12 He has not yet developed AIDS. He had this to say: 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 deathWhen you read about the disease in the papers it is like if you have this disease you might as well give up there is nonothing good can come out of it. The disease is very bad for people who are not able to help themselves, those who have nothing. To them it is very bad. You find that even the body of the person changes all the time. It changes The weight is not alright etc, etc

It is said that this illness has no cure. I am like a small child with a machine gun A gun which he can't use I am walking about with it (the machine gun)... By that I mean that I have HIV/AIDS but it is necessary that I should be helped but I am not being helped. I am overburdened with problems but nobody is taking this burden off me.

A13 I had fever, difficulty in my breathing, and feeling cold. I thought it was only flu. I went to hospital many times. I felt that they should check me for TB. I was checked for TB. The results took a long time to come and the results were inconclusive. It was found in the pain, in the chest. Then I continued taking anti TB pills. I drank them.... They made me get a rash; have swelling of the body and swelling of my private parts. There was no progress, things did not get better. Then I was checked for 'the germ'. Then I went for checking of 'the germ' because I felt.... I felt from the signs that you can have a rash, you can have a headache because I had a headache. I was checked and told that I am positive. Then I stayed. I continued taking anti TB treatment. I did not get better though I was I changed every day. One day I am better, the next day I am not better. I develop a rash.... The following day I have a rash in my private partsIt was many things changing in me until my CD4 went very low. Then they put me on ARV (anti retroviral therapy)The only problem I had was dizzinessmy CD4 had gone down to 180. Then they started me on ARVS.

A14 She has not yet developed AIDS. She had this to say:really the first thing, 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.

A15 Really this illness when it first arrived people did not take it like any other disease. It was taken to be a devastating illness such that if you knew you had the germ, you would think that you would be dead the next day. They talked about it like if you have this illness it means you were a prostitute.

A16because when you are told that you are HIV positive, you knowI to me it was like I was living one world/country and I was entering another world/country... if you are told that you are positive, thoughts come... 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, because when it started, HIV was thought to be due to the person having been a prostitute, promiscuous, etc. So you have to deal with all these things to begin with.

A17 They told me that at the beginning, the drugs I was taking could make me feel more ill. In other words, the drugs have side effects. And at other times it can happen that when I take them, the side effects would come but after a while everything would be normal. I suffered from side effects for eight months. I was very illafter I started taking medication until I completed eight months. I kept coming and telling the doctor. But the doctor told me to continued taking my medication. I continued taking my tablets. After eight months, I started getting back to my old self (feeling like my old self). I got back to good health.

Care-givers and social workers:

A1 I bother them with eating. It means that the one who is looking after me is now tired. She is now tired because when I tell her that I am hungry she says, "Person of God(common expression with no religious content) when you eat at such a high rate when I am trying to cook for you, how many times do you want to eat in a day?"such things They shout angrilyha ha. They shout angrily. They say I eat lot.

A2 Just now, you see, I stay with my nephew. He is concerned about himself only. As for me, honestly he is far away from me. It is like he does not know that I am his uncle. The mother of this one who is called my nephew, she is taking care of the family home (at the village). No he is completely unable (useless). He says that he has children. You see when someone says this to you he means that you must get away from him and not make your heart painful. It means you must get out of him, see in what way you can live.

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 timeand you do not get any feedback.

A3here also (hospice) I receive helpand the council (Gaborone City Council) gives us food. My problem is accommodation. It is so congested that I thought I would go and ask for accommodation from social workers. Since I stay with parents they will not agree because they will say I should stay with my parentsbut again, staying alone, if I get very sick at night nobody will see meAt home really there is no problem. The only problem is accommodation. Really there is nothing I can complain about (at home).

A4 Where I stay, eh – I am not well taken care of. You see it is my aunt who takes care of me. Now, the life I lead is a very lean life (difficult life). We do not live well because, the old lady (aunt) is the only one working. She does everything, like the house She pays for the plot, water, electricity, etc. She buys food. Nobody is helping her... She is the only one who is helping me – the old lady, by caringThese young people who stay at home, when I ask them to wash for me, they don't agreeSometimes when I ask a person (the young people) to make me porridge, they refuseNow 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. I was really having a hard life. Now spending the day here helps meThe doctor wrote a letter. I took the letter (to social workers) today. They say they would have come (to where I stay), the problem is they have no transport. They say they will only come next week.

A6 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. I went and got food once only. It is the very food we are eating now. When I was supposed to go and get food again then they stopped me and said I should wait. "Au! Why do I have to wait?" "No your letter is not well." "My letter is not well in what way, because my letter is from the doctor / hospital. The doctor sent me with this letter to you." "No it is not well, it is not well." Even now they say I should not go to them. I should wait for them but our food is getting finished... At night sometimes when I have problems ... the old man of God because he is short sighted ... he will unlock his door there and come to knock at my door, then I crawl on my knees to the door so that he can come in. Then I unlock and he comes in. "What is wrong?" "I have a sharp pain." The lady who stays in our home then comes to massage meWe at home really, we have a difficult life but we are in good terms (we hear each other).

A7 I have children who go to schools. "There's nobody who helps them," I said a few days ago in March, telling the nurses, because there was nothing we were we eating. 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 in the month that has just ended.

Our problems which I want doctors to know is that if we can be helped if you are not living well. With social workers to help the children when you are ill because these days they pay at school.

A8 I mean my sisters did not They did not take care of me like my mother would have if she was alive. The small children were the ones who were helping me. Now you see if a child is helping you, at the end a time comes when it's like the child gets tired. So I stayed with a painful heart. You see staying alone (without company) is very heavy (difficult)....I was asking myself, really, my sisters, why were they not visiting me.They did not If they came at all it was not likehere we are nursing a sick person. You see the thing that hurt me the most was even buying food, they were unable. You see. They were not able totallyyou see when you are taking care of an ill person, you have to check if the ill person has something to wash with (soap); is as she is supposed to. If I have to go to hospital, I had to come and tell the people of this place (hospice), "I am physically unable to go by myself, please come and fetch me and take me to hospital." So when I spoke with my cousin she said, "person of God, come and stay with me. Maybe you can get better." So I moved to Extension 14 (to my cousin)Then I stayed and stayed and started getting a lot better like now. I changed from the state I had been in when I was at home (Old Naledi).

A10the old lady cannot be able to keep on feeding me when I am this age. Now she only does it really because I am her son and I am ill. There's no one she can throw me to. ...even if she is not able I mean that it is not the same as if I had been lost (had no one to go to) because as for maize meal I am able toto have a small plate of corn meal (diminutive is not to be taken literally) to bring back the air (maintain life)... . It means I just suffer on my own like you see us coming here (to the hospice). These ladies of here, haisometimes, some white ladies sometimes bring torn clothes (old clothes) and they give to us.

A11 I stayed with my parents, that is, elders in the home. They are the ones who nursed me, taking care of me. I could not do anything for myself that time.

A12 At home it is difficult because everybody... They drink alcohol, and when they have drunk beer everything is alright with them...None of them gives me a hard time. All of them say they will help even though they can't.

A13 Really when I started getting ill, and my illness got obviousI was accepted by the parent who breastfed me. Even my siblings, they did not treat me like I was the child of their mother. 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 itThe social workers took my name. I don't remember when. This is the third month that I am getting free food. They say this arrangement is temporary, its for six months.

A14 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.

A15 ...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 BotswanaI don't know how you are. See, now you are 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. Such that 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?".

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 socialworkers only help people who are very sick and incapacitated, those who are bedridden.

A16 This interviewee did not make a contribution on this subject.

A17 My mother accepted me and I also told my brothers, they alsoreally they helped me.... One of my brothershe is here in Gaborone said to me, "by the way if you go home (rural area), there's no hospital there. You should stay here (Gaborone) near the doctors". Then I asked him how I would pay rent. Then he said he would pay for my rent, until I get well. He did as he promised and continued to pay for my house for a year and six months-he was giving me two hundred pula for rent until I was well.

My child was attending school in RamotswaMy brother continued to help me by giving him money to go to school every morning... my younger sister who died, she had the germ, but she had not yet tested (for HIV). She had a small child. Even her child had the germ. It is like my other younger sisters at home, they used tolike this childthey used to say she should not eat with others and should not use the same utensils as other people. Her utensils were hers alone and she should eat alone. . Now I have another brother who works in a hospital, at Princes Marina. When he came home I used to tell him about this. He talked to them, my younger sisters, telling them "you should not discriminate against this child. You can use the same utensils as the patient. This illness is not spread by using the same utensils as the patient"

....even the social workers if you go to them and tell them that....myselfmy health....even theyeven if they help you, they tell you that they help just for a while. But when your health gets better....if you go to them....because I tell them "my health is better but I can't find a job. Cant you just help me becausethere are councilsthey should look for jobs for us so that we can be trained". They say they are not able to find jobs for us. (They say) it's up to us to struggle on our own. Even soreally....the very social workers....its likeits like they don't care to

assess.....like they should come to your home and asses your lifebut really your health may be better but the means to support oneself, may be absent completely. Its like they don't careif you're not wellif you are well, you are alright (to fend for yourself), they leave you.