

Experiences of having HIV and the support of a community organization- a qualitative study

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Abstract

The objective of this qualitative study was to explore how six South African HIV-diagnosed persons experience the social and emotional consequences of being infected and how the support structure provided by the non-governmental organization Keiskamma affect their everyday lives.

The qualitative approach consisted of semi-structured interviews with six of Keiskamma's patients and observations of the village inhabitant's life in the Ngqushwa municipality, Eastern Cape to give a wider picture of the respondent's context and life situation. Theories used to analyse collected data was stigma (Goffman 1973), sense of coherence (Antonovsky 2005) and coping (Lundin *et al* 2009).

Six themes were identified: faith, knowledge, network, belonging, people's view of them, frustration and emotions during the time of diagnosis, these together increase our understanding of how it is to live with HIV in rural South Africa at a micro level. However, deficits at macro level were also identified that interfered with the respondent's quality of life. These are poverty, lack of access to health facilities and bad roads. Through advocacy and collaborate efforts in cooperating with the Department of Health the Keiskamma tried to bring a change to their situation at a structural level.

A difference found was that the village of Hamburg, where the Keiskamma was located, had less HIV stigma and the disease was more explicit compared to the villages outside. This can perhaps be viewed as an unequal knowledge distribution and the impact of the work Keiskamma did.

Keywords: HIV, AIDS, experience, community organization, Keiskamma, South Africa

Preface

Ever since I can remember I have been interested in going to Africa because of charity campaigns in Sweden about the poverty. Being granted the Minor Field Studies scholarship gave me the opportunity to travel to the beautiful village Hamburg, in South Africa. The trip was the most worthwhile time of my life. I got in contact with Keiskamma through a former cooperation between Lund's University and the organization.

I would like to thank everyone in the village and the organization Keiskamma for their hospitality and kindness. This thesis would not have been possible to write without my supervisors Magda Greyling and Thandi, thank you for your help and support during my stay in Hamburg! I also want to thank my interview respondents for taking their time to answer my questions and sharing their experiences. Last but not least, my supervisor at Lund's University, Lars Harryson whose motivation and knowledge has helped me write this thesis.

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1. Introduction

Human Immunodeficiency Virus (HIV) is a virus that progressively fails the immune system and therefore allowing life-threatening potential infections and cancers to spread. The HIV virus destroys or kills the CD4 cells (T-helper cells) that helps the body fight off infection and disease (CDC 2007). As the virus progresses, the immune system becomes weaker, and the infected person becomes more susceptible to infections. HIV itself does not always have symptoms it is rather the secondary infections e.g. tuberculosis that give the main symptoms and threaten life (smittskyddsinstytutet 2010). It can take 10-15 years for an HIV-infected person to develop Acquired Immunodeficiency Syndrome (AIDS) which is the most advanced and severe stage of HIV infection. The HIV disease first appeared in the 1980's but became obvious in the 1990's and has only exploded since then. (South Africa, the world and aids 2010: 2). According to the Joint United Nations Programme on HIV/AIDS (UNAIDS 2009) there are today 33,4 million HIV-positive people in the world. The population of South Africa is approximately 50 million of which 5.7 million people are infected with HIV. Thereby South Africa is at present the leading victim of the HIV infection in the world. HIV/AIDS has led to a sharp decrease in life expectancy since the 90's. According to the World Health Organization, WHO, the expected lifespan in South Africa for women is 49 years and for men 47 years.

South Africa is divided into nine provinces of which the Eastern Cape is the poorest (Bainbridge *et al* 2009:55, 261). The tiny rural village of Hamburg where I wrote my thesis, lies in the municipality of Ngqushwa, Eastern Cape. According to Brady (2012) it is estimated that only 5.8% of the population have access to water inside the household. The unemployment rate is 76.5% and the average household income is USD159/month. 37% were being supported by government grants and 37% were on pension.

Given that HIV / AIDS is a major epidemic in South Africa I became interested in studying the social and emotional consequences of living with the virus. There are many Non Governmental Organizations (NGO's) in South Africa that reaches out to people in vulnerable areas, hence part of this study is to gain understanding for how the organization Keiskamma works with people who have HIV / AIDS and how their efforts help people when it comes to managing their disease and improve their daily lives.

1.1 Aim and objective of the study

My main aim is to increase my understanding of how people experience living with HIV in South Africa. Through a qualitative approach my objective is to explore how six South African HIV-diagnosed persons experience the social and emotional consequences of being infected and how the support structure provided by the non-governmental organization Keiskamma affect their everyday

lives. My main research questions are:

- How are personal consequences of living with HIV socially and emotionally?
- What type of help and support are the patients offered by the organization, and how do they experience their impact on their ability to live an everyday life as functional as possible?

I am aware of that through this premise I took for granted that there are social and emotional consequences of living with HIV and that Keiskamma's support structure are influential in people lives. I will approach this dilemma by lifting findings even if/when they go against my preconceived notions.

1.4 **Keiskamma before and now**

The information in this section has developed in conversations with representatives of the Keiskamma organization. Dr Brady, the new employed doctor, social worker, Greyling who also was my supervisor and executive director of the organization, Thabang. They all had contacts both in the community as well as the organization.

Dr. Baker, who is a medical doctor and founder of the Keiskamma came to the rural village Hamburg to do arts. She taught women in the village embroidery, various crafts and arts so they thereby could become economically independent but she could not avoid seeing the poverty and health issues in the village. In 2002 she started the Keiskamma which is a NGO to address AIDS related health issues. During this time the South African government was still discussing if they should supply patients with Anti Retroviral drugs (ARV's). Keiskamma took an initiative while they were debating and became the only organization providing AIDS/HIV treatment in this area of South Africa and at times had up to 200 people on ARV's. Many of these people stayed and died at the Treatment centre.

Due to ill health and severe poverty the long distances that people have to walk to sites offering necessary medical care results in that they do not attend the health facilities until they become critically ill. The treatment center was a residential care facility for patients having somewhere to stay while being prepared for ARV's treatment. At the treatment center full time in patient care was provided for those in need. Since medicine was not provided by the government money was collected to the organization through art projects and private donors. The money collected was spent on medical supplies.

The Keiskamma was established to fill the gaps that were not provided by the government. In 2004 the government started supplying ARV medicine because they realized the need was immense. As the services provided by the government changed, the Keiskamma needed to adapt. That is why

they started off as a treatment center but once treatment was being provided by the government, all the patients were referred to public clinics. A step down unit for patients was established at Nompumulelo hospital in Peddie. Therefore there are no more patients at the Keiskamma treatment center. At that time the medication was only accessible in the bigger cities and hospitals which meant that for rural areas like Hamburg distance issues were a matter of access to health facilities and ARV's. Keiskamma had an important role during this time since they would collect medication from the bigger cities for the patients on treatment. In 2009 the government started distributing ARV's to rural clinics. Now the organization deals with 47 villages with long distances between and bad roads, thus a Village Health Worker (VHW) is employed in each village to monitor the patients there. The VHW are co-operating with nurses in the 24 surrounding clinics. The clinics address diseases like tuberculosis and HIV/AIDS. Together they encourage the patients to do regular medical checkups so diseases do not get severe, education in hygiene, information about mother-to-child transmission and motivate people to test themselves against HIV. The VHW do monitoring, which means that they regularly meet with the patients to ensure that they adhere to their medication as prescribed, it has been an important part of their work since patients often default.

The treatment Keiskamma offers HIV positive individuals is inspired by a holistic perspective which means that they do not only treat the physical symptoms but also the social by e.g. education through AIDS and HIV campaigns and by distributing food parcels.

“We strive to address the challenges of widespread poverty and disease through holistic and creative programmes and partnerships” (Keiskamma’s Webpage 2012).

There are four programs that make up the Keiskamma: The Art Project, Health Program, Education Program and the Music Academy.

Keiskamma provides the community and their patients with different services.

An important issue that the organization addresses currently is the transportation of patients to public health facilities. The public transport is not developed and the poor villagers lack the money for transport. Transporting patients to necessary health facilities with long distances has been an important part of their work.

The organization offers support groups to HIV positive, educating in gardening and nutrition which are important in the fight of the virus. They also offer GOGO groups which is grandmother support groups, since grandmothers are commonly caring for orphans and vulnerable children, and they run various camps 4 times a year for adolescents, assisting them in grieving after losing someone close and providing information about safe sex and HIV.

During campaigns they spread knowledge about “prevention of mother to child

transmission“(PMTCT). They offer counseling to the 54 VHW in the 47villages.

Finally there are 3 “orphans and vulnerable children” (OVC) centers. They offer opportunities for children to go after school to study, play and eat food.

1.5 **Economic support**

I focus on the health section of the organization. It is mainly funded by Canadian International Development Agency (CIDA) in co-operation with Primate’s World Relief and Development Fund (PWRDF). CIDA is a governmental organ and their mission is to lead Canada's international effort to help people living in poverty in different parts of the world (Canadian International Development Agency 2013). They have been funding Keiskamma for 5 years and will fund it for an additional 5 years. They fund for specific things like petrol for the vehicles, as well as training of the VHW, salaries for VHW, the doctor and social worker.

There are many other donors, both private persons and organizations that contribute to the music, art and education programs, to mention a few donors: Stephen Lewis Foundation, Bjorn Ronneburg, the European Union and Hospice and Palliative Care Association, South Africa.

All funders want reports sent to them to see what the money is used for and how the work is proceeding (Keiskamma’s Webpage 2012, Keiskamma 2010).

1.6 **Annual reports**

Evaluation is important since it provides an overview, for this reason most donors want annual reports, this is a kind of evaluation. The name of an annual report template is e.g. “performance measurement framework”. This can thus be a burden for the organization since it is often not only one donor rather it is 5 donors or more. Writing one annual report is heavy work so writing many can therefor have a crippling effect. In conversation with Dr. Brady, doctor in the organization she said that evaluation should be for better quality but all the focus and work goes to the reports so it affects the work the organization really should be doing. Writing several annual reports per year was experienced as unrealistic expectations.

Further Dr. Brady said that Keiskamma is doing the work government should be doing but they are not funded by the government so instead international donors help economically for providing services that the government should be providing for e.g. transportation and access to health facilities. Donors are necessary for their work and highly appreciated but the backside is that donors most often set the agenda of what is important, what the focus will be and what work that needs to be done. This result in that organizations do things that are not a priority but the problem is that they can only get funded for certain things. Donors know this but they help in such way they think is most beneficial.

1.7 **Advantages and disadvantages of community organizations**

Inhabitants in communities have the capacity to identify problems and solutions since they are participants of the every-day life (Cotrell 1983 in Minkler, Wallerstein and Wilson (2008: 293). Engaging in community organizing, an empowerment outcomes that "... can include an increased sense of community, greater participatory processes, and community competence, and outcomes of actual changes in policies, transformed conditions, or increased resources that may reduce inequities. As communities become empowered... social problems may begin to decline." (Minkler *et al.* 2008: 295). The grass root participation is the most important because that is where the real and visible changes take place. Therefore it is of interest involving the organization and the villagers in formulating the problems and possible solutions.

Further, I can see some possible disadvantages of community organizing, that is if volunteers and communities often solve their own health issues the government may "relax" and put all responsibility on them which will result in that they do not provide to the extent they should. Health community organizations in different areas may vary a lot in supply, economics and engagement which will make the quality of the health care geographically bound which is not fair. The help the organization reaches out with is restricted to a local area and not everyone can take part of it due to e. g. traveling expenses and ill health.

1.8 **Advocacy**

London *et al* (2012) writes that advocacy is an activity that includes an individual or group who aims to influence public policies. In this case health resource allocation decisions within politics. London *et al* (2012) writes that within the health sector in South Africa, the socio economic rights for the population is severely unequal. It has left the most marginalized people in society particularly vulnerable. There is a gap that needs to be filled in terms of improved access to quality health care. The psychosocial support and services are not fully being provided either. For the inhabitants of Hamburg it has not been easy to get their voice heard because no one has been listening. The successful way of advocacy has been through the art Keiskamma makes. Through art they tell the story of all the people that died of the HIV pandemic. Their next goal is to recruit a medical doctor. At the moment there are 24 clinics and one medical doctor, Brady, but she works with advocacy and training the VHW so there is no employed physician that meets with patients and the need is huge. The organization is trying to do this in partnership with government, so that the government pays for the physician's salary rather than aid organizations (donors). The organization experiences so far with the representatives from the state are that they do not come to the meetings, they are reluctant because of corruption or they do not have the skills. Dr. Brady said

that there is no transparency and accountability. Through Keiskamma vulnerable people are thus trying to change their condition at a national level. The focus is access to proper health care, medical doctor, psychosocial issues, in other words more resources. The community organization deliver necessary services that should be the state's responsibility. The potential tension arising from grass root action is that the state might be relieved of its obligations. London *et al* (2012) writes that through advocacy civil society can play a key role in bridging a gap between formal state commitment to realize services and policies that enable the most vulnerable members of society to advance their health. Advocacy highlights the importance of civil society's capacity of networking with government to gain their human rights, like access to health. Through advocacy the Keiskamma is filling the communication gap between the village inhabitants and the government.

1.9 **Background about the spreading of HIV**

One of the main factors behind the wide spread in South Africa was the political denial of the virus (Hart 2010:2). President at the time of 2000, Thabo Mbeki, denied the scientific evidence that HIV causes AIDS and has had a passive role in the fighting against HIV/AIDS (Cohen 2000:590-591). He gave misleading information to the public that food products such as beets are more effective for treating AIDS than antiretroviral drugs (Nature 2007). President Mbeki considered the virus being a socioeconomic problem since it is more spread among the black, poor and uneducated people (South Africa, the world and aids 2010:2).

Joint United Nations program on HIV/AIDS 2009 AIDS epidemic update is a report dealing with the AIDS epidemic in different themes, among one of them is how the epidemic is in Sub- Sahara Africa. The report is based on national, anonymous household surveys that were made during the period of 2007-2008 in eleven countries, of which nine of them were made in Sub- Sahara Africa.

The survey shows that Sub-Saharan Africa remains the region most heavily affected by HIV worldwide, it accounts for 67% of all new HIV infections in 2008 (UNAIDS, 2009: 21).

Women and girls are more affected of HIV in Sub- Sahara Africa, 60% for example in West- Africa the incidence of HIV among women was more than two times higher than men in 2005. Women's vulnerability to HIV in Sub-Saharan Africa depends not only on their greater physiological susceptibility to heterosexual transmission, but also on serious social, economic and legal disadvantages they often face. In Lesotho, which is a monarchy in southern South Africa it was found that sexual and physical abuse of women are important causes of the nation's grave HIV epidemic. It also emerged that 47 percent of men and 40 percent of women say that women do not

have the right to refuse sex with their men or boyfriends. Women's unequal position in relation to men increases their risk of contracting HIV. In the nine countries in Sub-Saharan Africa where the HIV epidemic is at its worst, the incidence of HIV among young women aged 15-24 is about three times higher than among men of similar age.

The report addresses other key factors that contribute to the spread of HIV. Heterosexual intercourse remain the main cause of the spread of HIV in Sub-Saharan Africa with ongoing transmission to newborns and infants during lactation. In Swaziland, transmission during heterosexual sex is estimated to account for 94% of incident infections. Other key factors are sex workers and their clients, men who have sex with men and injecting drug users (UNAIDS, 2009: 21-26, 29).

As mentioned, the transfer of HIV from mother to child is one of the major causes of new HIV infections. In 2008 it was estimated that children in Swaziland have around 20 percent of all new HIV infections. Indications suggest that a small part of these infections in children under the age of 15 can have been caused by rape or other sexual abuse.

An additional reason for the spread of HIV is the prevalence of other sexual partners outside marriage, which is allowed in some African countries as in many other parts of the world. In Uganda men aged 15-49 who reported having multiple sexual partners increased from 24% in 2001 to 29% in 2005. This resulted in that 46% of all new HIV infections were estimated to have incidence among people with multiple sexual partners and the partners of such persons.

People who have higher education and income, have also better and more knowledge about HIV and are thus better equipped to prevent getting infected by the virus (UNAIDS, 2009: 30, 35).

2. Previous research within the area

There has been a lot of research conducted in other nations, e.g. USA, since HIV/AIDS is a global phenomenon. However, I have chosen to limit “previous research” within the field of social, emotional and coping aspects of living with HIV in the continent of Africa. Below I will present the studies I have chosen. The first study: “Older Female Caregivers and HIV/AIDS-Related Secondary Stigma in Rural South Africa” is relevant because it shows how the patients are socially affected by the virus. The second study: “Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa” highlights the emotional aspects and experiences of living with HIV. The third study “Faith, spirituality, fatalism and hope: Ghanaian women coping in the face of HIV/AIDS” explains how HIV positive people cope with living with the virus.

“Older Female Caregivers and HIV/AIDS-Related Secondary Stigma in Rural South Africa”

is a study made by Ogunmefon, C, Gilbert, L and Schatz, E (2011). The study is based on interviews with 60 female caregivers. The authors write that the negative attitudes towards HIV are stimulated by local or cultural beliefs about the illness and its causes. This results in that HIV positive individuals often are stigmatized by their families and community (Castro and Farmer 2005; Gilbert and Walker 2010 in Ogunmefon *et al* 2011: 86-87). Often, the stigma is extended to those who are close to the infected person, especially their caregivers but also family members. The fear lies in the risk of being infected and therefore no one wants to socialize with HIV positive people. (Posel 2004:23 in Ogunmefon *et al* 2011:87). There are many studies according to the authors that highlight the stigma experienced by HIV/AIDS positive. It is difficult to talk openly about the subject and people who carry the virus keep it a secret due to fear of being excluded from family, partner, friends and neighbors. (Ogunmefon 2011:91).

“Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa” is a study made by Leickness Simbayi, Seth Kalichman, Anna Strelbel, Allanise Cloete, Nomvo Henda, Ayanda Mqeketo (2007). The study examined the occurrence of discrimination experiences and internalized stigmas among 420 HIV-positive men and 643 HIV-positive women. It is based on anonymous surveys recruited from AIDS services in Cape Town, South Africa.

The consequences of internalized AIDS stigma have not been investigated in the continent that is home to two-thirds of the more than 40 million individuals living with AIDS in the world. This study shows that discrimination experiences and internalized AIDS stigmas were common among individuals living with HIV/AIDS in Cape Town.

People who are HIV positive are often blamed for their condition because HIV infection is associated with risk behaviors that can be avoided such as unsafe sex and drug use. AIDS stigma is also closely related to other stigmas that are associated with HIV risk behaviors, for example homosexuality, drug use and sexual promiscuity.

AIDS stigmas interfere with HIV prevention, diagnosis, and treatment. The reason why is that people know that they will be treated differently by family and friends if they find out their HIV status. People that are unaware of their HIV status reported that stigma influence their decision not to get tested. Of those who get tested 60% of the sample said that they had not told anyone about their HIV infection in fear of negative reactions and exclusions.

The result of the anonymous surveys was that 40% of the survey participants had experienced discrimination resulting from being HIV positive and one in five had lost a place to stay or an employment because of their HIV status. It is common for HIV positive to blame themselves for being infected with HIV, as many as 30% of the participants said they felt dirty, ashamed, or guilty.

About 20% of the survey participants had never talked to a friend about their HIV status. One in three, of those who had told friends/family their HIV status was afterwards treated differently. (Simbayi *et al.* 2007: 1823-1824, 1827, 1829)

Internalized stigmas were common in their sample of people living with HIV/AIDS. More than 30% of the participants admitted feeling humiliated of oneself and guilty related to their AIDS status.

The author writes “People living with HIV infection have internalized AIDS stigmas to a far greater extent than these beliefs are held in the broader community.” (Simbayi *et al.* 2007:1829). An example is that 16% of the survey participants thought that HIV infected should be ashamed of themselves whereas 38% of people with HIV said they felt ashamed. 13% considered that HIV infected has their selves to blame for the infection compared to 41% of HIV infected that felt guilty for being infected with HIV.

The research was made in the capital of South Africa, which is a city with greater economic resources than other towns and provinces in the country. The health and emotional well-being of individuals living with HIV/AIDS in this research may therefore represent a more optimistic view than in other areas of Southern Africa (Simbayi *et al* 2007:1829).

“Faith, spirituality, fatalism and hope: Ghanaian women coping in the face of HIV/AIDS” is a study made by Perry, Davis-Maye and Onolemhemen (2008), the authors tried to find out how African women cope with living with HIV/AIDS. Findings of their study suggested that the women’s religious beliefs contributed to their resilience in coping with HIV and other difficulties in their lives. Their faith allowed them to maintain hope since it did not limit their ability to believe that the power of God to miraculously change the circumstances of their lives. The reliance upon spiritual faith seemed to increase across time and illness progression. The study indicated that absolute faith in the dominion of God can be linked to the women’s acceptance of their HIV status and other significant life events as the will of God. Faith appeared to be liberating and disempowering, it also seemed to limit the extent to which they could envision themselves as having the ability to shape their destinies (Perry *et al* 2008).

3. Performing collection and data analysis – an assessment

The inductive design is more exploratory than the deductive design where one is driven by theories and expectations (Wood, Giles & Percy 2009:65 and Bryman 2008:40). Since I was in an unfamiliar

and new environment it was suitable for me to take on an inductive design where my genuine interest led me to a greater understanding. My main focus in the research was: exploring how South African HIV-diagnosed persons experience the social and emotional consequences of being infected and how the support structure provided by Keiskamma affects their everyday lives. The most appropriate way to collect information for my research was through a qualitative approach consisting of interviews and observation. It should be emphasized that observation was not used as a method, rather a complement to the interviews to give an understanding of where I have been.

3.1 **Qualitative approach- Interviews**

There are some characteristics of the qualitative approach that Bryman (2008:340-341) addresses. The qualitative research describes, observes and listens to individual experiences. I was interested in subjective experiences and to be able to take part in the depth of a person's feelings and experiences I needed to meet individuals face to face.

Selection is mainly about choosing individuals or organizations that have strong relevance to the research question (Bryman 2008:350). I did not have any criteria on the interviewees other than those already imposed by physical location and people who were present during my stay. My only restrictions were regarding age span, I wanted to interview 18-40 years old but the circumstances rose the age to 64. I did not want interviewees below age 18 to participate since it would be unethical to interview children, the subject HIV is of sensitive character. It was through my field supervisors in the organization of Keiskamma that I got in contact with their patients.

All of the respondents were HIV positive and had more or less active contact with Keiskamma. They were all asked by my supervisors and me if they were willing to be interviewed and three of the participants said yes immediately while the other three were uncertain but chose to participate after doing some reflection. It was difficult to get hold of male participants. Of all dozen that were asked, finally one man was willing. The interviews took place in different locations; most of which inside Keiskamma's building but in different rooms and some of them were made when we were out on AIDS campaigns in villages close by. I would like to introduce them briefly to give an understanding of who they are. It was one male and 5 female. Four of the females worked in the organization with different things like gardening, support group leader and VHW. The male had part time jobs and a woman was unemployed.

Using semi structured interviews made it possible for me to adjust to every unique meeting. May (2011:134) explains that the questions in the semi-structured interviews are specified but the interviewer is free to ask for clarification or ask deeper questions about topics relevant to the study when needed. The interview can become more of a dialog instead of a monologue. The variations of

the answers in the different interviews were significant but each interview added to the final story. I had my main questions in focus and those determined the subject of the conversation. A methodological weakness of interview is that narratives that are told by the respondent may not be interpreted by the researcher as they were intended to (Eriksson-Zetterquist and Ahrne 2011:56). This was solved, when feeling uncertain, by asking the interviewee if it was correctly understood. The interviews were recorded as a help for the memory. According to May (2011:151, 152) recording an interview higher the validity and reliability. This allows the interviewer to concentrate on the conversation and enhance the non-verbal behavior instead of frenetically writing notes. When interviews are recorded they need to be transcribed which means that the material caught on tape needs to be written down as a text. Further May (2011:152) writes "Then, editing the tapes, according to categories in which the analyst is interested, assist in the comparative analysis of the interview responses." As the author shortly explains it is up to the analyst to categorize the dictum of the interview in desired way to be able to see clear patterns of the research issue. During the transcription I did a thematic analysis which means that I focused on what was said rather than how it was said. A usual criticism towards coding data is that the context and narrative flow goes lost (Bryman 2008: 526, 527). These methods I thus needed to be able to bring out the most essential parts of the narrative. I followed Giorgi and Giorgi (2003) in Wood *et al* (2009:147) description of doing phenomenological analysis. The first step was to read through all the transcribed interviews without any predetermined categories. Doing this means giving attention to parts that otherwise just would have been skim over or considered irrelevant. The second step was re-reading the interviews using pens in different colours to start identifying the interesting parts. After processing the interviews six recurring themes were identified and labeled. Those I have written about in the results and analysis. I used for instance orange colour when I could relate the narrative to the theme "faith". The last step was to give a meaning to the quotes chosen in the narratives, which was to explain the themes and quotes with the help of the theories stigma, sense of coherence and coping. The final work should enable the reader to understand the experiences of living with HIV without reading the whole interviews.

Wood, Giles and Percy (2009:145) writes that one need to be clear on knowing if the deductive or the inductive designed was used whilst analyzing the data. Deductive design in this setting means that the interviews were coded into categories chosen in advance and the inductive design means that the interviews were coded into categories developed in the process of analysis. I mostly used the inductive design since after reading the interviews with an open mind I created themes that were collected through recurring quotes. When the themes were addressed, I tried to understand them with the help of the theories stigma, coping, sense of coherence and previous research.

3.2 **Observation**

As mentioned earlier, the main method used in this study was interviews. Observation was used as a complement to increase our knowledge of the settings and surroundings I was in. I will therefore not analyse material collected through observation rather explain and describe. According to Kenneth Bailey (1987: 239-240) observation involves collecting data through sight, hearing, touching and smelling. This method is preferred when wanting to collect the nonverbal behavior. Except from the verbal dictum from the interviewee I saw the actual life situation of HIV infected which clarified in what way the patients were affected by what was specified in the interviews. The initial plan was that the interviews would be followed by an observation of the day-to-day life of the patients and employees in their natural environment at Keiskamma, to give a wider picture of the organization. I thus had to change my plans of observation because the organization did no longer have in-patients. I had expected being in a clinic where patients were staying but the organization did not take patients in to the clinic because they now referred the patients to the public hospital Nompumulelo. Instead I was given the opportunity to comply with the social workers to villages where the locals lived. I visited and saw the villagers housing, family and listen to their stories about what issues they were having. The prolonged stay in the social environment can make one suited to perceive things like other do (Bryman 2008: 440). Much of the articles under "previous research" highlight concepts like stigma and social exclusion so I was paying attention if seeing such treatment of the HIV infected persons. (May 2011:180-184). Observational notes were written as help for the memory.

My role was a participant observer which means that I was a part of the natural environment but in an *open* way. The observed persons were aware of my role as a researcher and observer (Wood, Giles & Percy 2009).

3.3 **Validity**

Validity and reliability are related to one another and taking these into consideration higher the quality of the research. Validity means that you actually investigate what you aim to investigate and nothing else. "*Validity* is about demonstrating that your scale assesses what you intend it to". In relation to my study this means that my interview questions must be formed in such way that the outcomes of the answers are allowed to match what I am asking for (Bailey 1987:175, 266). According to Bryman (2008:352) external validity is the extent to which the results can be generalized to other social settings and situations whereas the writers Ahrne and Svensson (2011: 44) clarifies that one need to interview at least 10-15 persons to gain a data that can be representative for a bigger population. Since my study included interviews with only six persons the generalization level is low. The valuable information I gained in my study is addressed to

Keiskamma Trust since it is their work I had in focus.

3.4 **Reliability**

Reliability can be translated as trustworthiness, that your measure instrument is as exact as possible. Reliability is the consistency and repeatability of your measure (Wood, Giles & Percy 2009:124-125 and Bryman 2008:352). Since I will get my main data collection through interviews I am aware of that respondents may answer in a socially desirable way (but inaccurate) because of loyalty to the organization (Bryman 2008:224). Other factors like sleep and memory influence all humans and there for narratives can slightly change from one day to another. In interviews where I needed an interpreter the reliability was affected negatively since the interviewee's intentions and explanations were modified by the interpreter. One can try to get a skilled interpreter but it may still not be as good as to be without one. In two of my interviews an interpreter was used because the respondents could not speak English well and this may have influenced the reliability of the essay in a negative way because in the interpretation important information may have gone lost. According to Kvale & Brinkman (2009:160) the interpreter's role is to assist and not take over the interviewers or interviewees' role. I did not think there were issues in role boundaries rather I was not sure how exact the interpretation was made since I could not master the Xhosa language. The interviews conducted without an interpreter was not in all cases optimal since some interviewee's did not have a large English vocabulary and that limited their ability to fully express their feeling and thoughts. However, the interviews were very informative.

3.5 **Collecting knowledge**

It has not been difficult for me to find relevant and useful information for my study. I have acquired knowledge about the subject HIV from the database SOCIndex with keywords: HIV, and AIDS in Africa/Sub-Saharan Africa/South Africa, emotions, experiences of living with HIV, South Africa. I have read books, student literature and articles; look below under "references".

4. Ethical consideration

I was aware of that I had a dependent relationship with the organization Keiskamma in South Africa because without their help I did not have access to the interviewees I needed for my data collection. They had no dependent relationship with me because I went there for the purpose of my thesis and I didn't provide them with anything they were in need of. The contact we established was through my initiative .When I have finished my thesis I will send it to the organization and its members, I hope that the knowledge that emerges from the study is helpful for their future work.

Moreover, I have previously not been familiar with HIV disease, I know no one who has it and in

Sweden HIV is not notably prevalent. When I decided to go to South Africa and write about HIV, I read more about it and became familiar with the subject. When I was at my field site and did interviews, I kept in mind that the subject I asked about was of a sensitive nature and the feelings that come up, I must be perceptive to.

The personal experience of living with a life threatening disease like HIV and AIDS is a very sensitive subject. Ethics were therefor prioritized but as in when researching in such sensitive field nothing can be 100 % harmless. Using a semi structured interview gave me room to ask further questions but I kept in mind that what I ask of would be of relevance to my study and not for curiosity. I followed the Swedish laws, regulations and guidelines of The Swedish research council to insure ethical correction. There are four principles that I worked after and introduced to every interviewee and these are explained below.

Confidentiality requirement: I clarified that all respondents would be anonymized in my study and that all material with personal information would be kept in such way that unauthorized people cannot benefit from them. All material with personal information will be destroyed as soon as my master thesis is approved by the university.

Autonomy: every individual has the right to make own decisions concerning his life. I did therefore obtain consent after given information about the purpose of the interview. All participation was voluntary.

Transparency requirement: Honesty and openness are key words to trust and are of ethical importance. I informed all participants about the research task and how all data will be used.

Self-determination: participation was fully optional. Even if one agrees to participate but later in the interview changes her mind she/he has the right to withdraw at any time. If any question is uncomfortable she/he does not need to answer. I tried to create an open climate in the conversations to give room to the interviewee for such statements (Vetenskapsrådet 2002).

Every informant was given my name and my phone number in case they wanted to contact me concerning the interviews or the interview material.

5. Theoretical approaches

Coping strategy has its main focus on the actions an individual uses to deal with and conquer problems that he/she is faced with in a difficult situation. Coping strategy is of importance when examining how individuals deal with events when their own resources are not enough. Furthermore, it also explains the strategies used when adjusting to a new situation in life. When dealing with a

disease, such as HIV/AIDS analyzing coping strategy is of paramount importance as it almost predicts how successfully the new situation will be mastered. Studies demonstrate that coping strategy must be developed and strengthened to improve person's ability to deal with the disease. (Lundin, Benkel, Neergaard, Johansson & Öhrling, 2009:112).

Sence of coherence is a formulation that gives a central explanation for the role of stress in human functioning. Antonovsky (2005) argues that, what determines whether stress will cause you harm is whether or not stress violates your sense of coherence.

According to Antonovsky (2005) sense of coherence has three components:

- **Comprehensibility:** outlines the person's ability to believe that events occur understandably and predictably. Conclusively, gaining an understanding of events and how they occur.
- **Manageability:** A persons beliefs of having appropriate skills, resources and support necessary to manage a situation.
- **Meaningfulness:** This point focuses on the belief that events, life is interesting. That the desired outcomes are worth aiming for and working towards

Antonovsky (2005) states that the final element, meaningfulness is of utmost importance. A person should persist, struggle and aim for survival feeling that it has a meaning for them. Motivation cannot exist without a sense of meaning, thus, his research outlines that a sense of coherence predicts positive health outcomes.

Stigma is a collection of attitudes and social structures that people hold in order to classify the world for easier understanding. Erving Goffman's work on stigma in the 1960's defines this word as "a judgment that is significantly untrue (Goffman, 1963:147). Stigma in relation to ill-health presumes that illness has occurred as a result of misbehavior, rationalizing the privilege of the well over the ill.

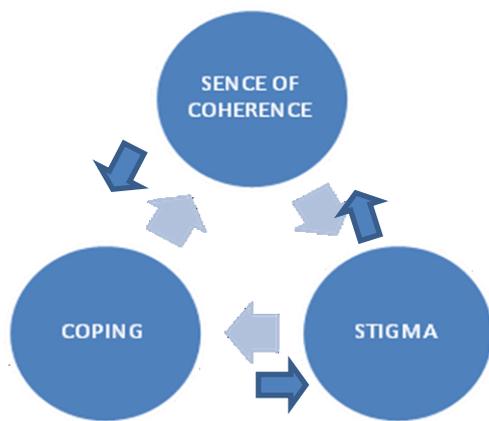
Goffman argues that stigma additionally divides a person or group from the larger society, giving reason for suspicion and hostility towards the individual. Being stigmatized is often a result of stereotypical opinions that carry no real facts (Goffman, 1973:28).

6. Results and analysis

The collected material, mainly interviews, after being processed was divided into six categories that were identified through recurring quotes. The themes were labeled: faith, knowledge, network, belonging, people's view of them, frustration and emotions during the time of diagnosis. The quotes are presented below under each theme with descriptions about the interviewee's life situation. It is what I think suits under each theme but it should be emphasized that I draw no sharp lines between the themes because I think they are mutually dependent on each other to increase our understanding of complex human living conditions. Some quotes fit in more than one theme, in such cases the quote is only written once to avoid repeating myself. Minor language adjustments in terms of grammar have been made. I have also removed sighs, laughter and thinking and other expressions that were not relevant for the study. For the sake of the interviewee's anonymity I have chosen not to give them fictitious names because I want to reduce the ability to create a coherent narrative of their life. The subject of the interviews has been sensitive, personal and private.

I have chosen to melt result and analysis together, thus under the heading "Analysis" the themes are more deeply examined through mentioned theories and previous research. The link between the respondent's narratives and how they actually manage their lives put in a wider context.

The three theories does not need to be loosely coupled from each other, they can rather be linked in a more coherent way to explain the impacts in the life of the interviewees. Coping, sense of coherence and stigma are mutually dependent of each other in such way that a change in one of the life aspects has an impact on all of the theories. An example is that if a person experiences shame, which is internalized stigma, then the sense of coherence is lowered. To higher sense of coherence coping mechanism are necessary. This chain is continuous and looking at it this way increases our understanding of how theories complete each other in this case. For sense of coherence to higher there must be coping mechanisms, otherwise there is nothing to higher a person's sense of coherence. For coping to exist there must be negative influences such as stigma because there must be something one need to recover from. When coping and sense of coherence is high then stigma is low and vice versa. There for I think that these theories are relevant in each individual's life and these theories are used to put the quotes in to a greater context. A model below demonstrates this, coping and stigma balances the sense of coherence.



6.1 Faith

What emerged in the interviews concerning experienced difficulties in life or events that were incomprehensible was that the interviewees found a comfort in God. The will of a higher power was in many cases stated as the reason behind the trials and tribulations the individuals endured. Below is two examples of when faith in God's plan made it easier to accept difficult situations. In relation to coping theory which focuses on how individuals deal and conquer the difficulties he or she faces, religion has a significant role in the lives of the interviewees.

“What worries me my sister died 2008 because of HIV, my other two sister are HIV positive but I don't want to think to much about that because I want to focus. They are on treatment. The other thing my sisters son died 2009 and he left three children: 1year, 4years and 2years. I'm supposed to look after them because their mother died 2001 in a car accident. But God knows what is going to happen with all of us.” The respondent was a person I got to know very well during my stay in Hamburg. She was religious and often went to church.

The VHW has a very important role in the village but they have many patients to look after and long distances to walk which makes their work hard.

“All the time I thank God for putting me here. Sometimes I said, like yesterday it was a hectic day for me when I think about the money but at the very same time God showed me that: this is the way I gave you. I really appreciate being here.” She had a passion for her work and was motivated to continue despite the sometimes heavy workload. Her gratitude to God was noticeable.

On the question is there anything in particular that makes life easier for you the answer another respondent gave was:

“My friends, Dr Baker, and the sisters at the clinic that has encouraged me. And church because I go to church on Sundays. I used to go to the church in Hamburg, the priest used to encourage me and I listen to gospel.” Faith in God, the competence of the medical doctor Carol Baker and the

interviewees friends are other factors that the respondent could find comfort in.

6.2 Analysis of Faith

Most of the people in Hamburg were religious and believed in God. They sang a lot of gospel, when there were larger gatherings, meetings and campaigns they sang in the beginning, during short breaks and in the end of the gathering. The songs created hope and joy. Of what emerged in the interviews both positive and negative events were related to God's will and plan. Faith in God's plan facilitated the process of accepting the virus and the sometimes struggling way of living. Perry *et al* (2008) confirms this, their study suggested that the women's religious beliefs contributed to their resilience in coping with HIV and other difficulties in their lives. Their faith allowed them to maintain hope since it did not limit their ability to believe that the power of God to miraculously change the circumstances of their lives. The reliance upon spiritual faith seemed to increase across time and illness progression.

I believe that it can also facilitate decreasing, to a certain degree, feelings of shame or guilt because it deprives the responsibility of people. If something is God's plan then the individual actions are not operative. The study indicated that absolute faith in the dominion of God can be linked to the women's acceptance of their HIV status and other significant life events as the will of God. Faith appeared to be liberating and disempowering, it also seemed to limit the extent to which they could envision themselves as having the ability to shape their destinies (Perry *et al* 2008).

Faith in the Keiskamma and Dr. Baker gave them the driving force to continue the fight against the disease in a concrete way. Those who were employed showed great satisfaction in the work they did since they believed in the organizations capacity to influence others. Their job was meaningful to them and for the not employed respondents it was meaningful for them to have access to Keiskamma and the services offered.

Faith is something meaningful since it gives comprehensibility to why things are happening. Faith allows one to abdicate responsibility to a higher power. Religion was meaningful to the interviewees since it raised comprehensibility of why events were happening and this as a result higher sense of coherence (Antonovsky 2005).

6.3 Knowledge

A woman with HIV that had healthy numbers of CD4 counts decided to take ARV's because her health impaired even though the CD4 count was fine. Her great knowledge of the subject HIV gave her confidence to go against doctor's recommendations and start the treatment again:

“... I was getting thinner, thinner and thinner but I was not sick. No TB nothing but I was thinner, thinner and thinner. I phoned the doctor and told her about my situation. She said I must come to take blood test, my CD4 was 437 and I was not supposed to be on treatment because you know the International Guidelines says below 350 one needs to be on treatment. I already knew what HIV was doing to my body so I asked the doctor to give me treatment. The doctor didn't want to but I had decided for myself. Now I'm fine because I'm getting bigger. I know there is a latent stage and I didn't want to get sick that is why I decided to take the treatment. I have no side-effects. I've got nothing. Now I'm fine.” Her knowledge of HIV gave her confidence to make decisions. She seemed to have a sense of control of the disease as she knew what might be going on in her body which gave her capacity to act upon what felt wrong. Another respondent says

“I don't hope and think I will die of being HIV positive because I've learned at the support groups what is right and what is wrong” Knowing how to live with the disease and thereby keep it under control helps cope and get an understanding.

One of my interview question is about if the respondent thinks that his/her life has been limited by HIV. If so, in what way? Most of the interviewees mentioned alcohol restriction and protected sex as the main limitations. Except from that they felt that they could live a normal life.

“I used to be a drunk person. I used to take alcohol with my friends but now after being HIV positive I know it's not good to be an alcohol person. So I can say yes. And I used to have unprotected sex but now I know that I have to do protected sex.”

Another respondent said:

“You are living like a normal person because you are doing the same things like other people but in your mind you know that OK, I won't do this because I have HIV” In support groups participants gain knowledge about how to live a good life with HIV and this knowledge increases their comprehensibility and therefor sense of coherence

The persons I interviewed that had knowledge about HIV and had an income tended to be more confident when it came to having protected sex. Everyone that has knowledge about HIV knows that it is important to have protected sex otherwise can other sexual transmitted diseases easily infect. One of the respondents said:

“I started an affair with a guy but we had to use condom because both were positive. He got fed up with the condom so I just left him. I don't want to stress myself to tell someone about condom, condom, condom.” I mentioned earlier that it is difficult for women to negotiate safe sex, but when women are financially independent and has knowledge about HIV they then seem to have better

prospects (UNAIDS 2009).

One of the interviewee decided to go test herself even though she didn't feel sick. She was surprised to see that her status was positive but she said that she was happy to know early.

“The problem is that people wait until they get sick. At that time it is no longer their own decision, it's the decision of the doctors, nurses or families. It is better to test earlier so you yourself can plan your life.” The respondent could decide and have control over the situation as she was feeling healthy and strong. When she was diagnosed she felt that she could manage and was happy to know before the virus had got the upper hand. Many of the ones she knew had first become seriously ill before taking the step to test themselves. Another respondent said that she first became very ill during a long time before she went with her mother and grandmother to the clinic. She was tested and the result was positive:

“I think they were surprised but they gave me a hug and said “oh, you must say thank you God for now I know what my body has” You have a disease of what so you can go to get help with that.”

The respondent had been feeling ill for some time so the family was relieved to find out what it was so she could get treatment. The knowledge to know what is going on in your body when it does not feel right is relieving because then you can go to the next step which is trying to manage and cope with the situation. Knowledge gives comprehensibility to the confusing situation and therefore higher sense of coherence.

This respondent came to the clinic for Early Childhood Development training and she appreciated listening to other people that were living with HIV, she said:

“As I look at her I don't see that she has HIV. I see she is normal and I see she is beautiful. So I see her as my hero” Maybe there are prejudices about how HIV people look and are, those prejudices broke when the respondent saw a HIV positive woman looking strong and healthy. Of what I could tell this seemed to have increased her confidence. Spreading this picture about HIV and that the people that have the virus are just as normal as anyone else breaks the prejudices, this is important in the fight against stigma.

6.4 **Analysis of Knowledge**

The people I interviewed had much knowledge about how to live their life with HIV in the best way. They had aspirations and hope of a healthy life since they knew how to maintain good health. I associate knowledge with sense of coherence. According to Antonovsky (2005) sense of coherence has three components: 1. Comprehensibility: which outlines an individual's understanding of events and how they occur. This component is about understanding what HIV is and how it contracts. The

second component is Manageability: which outlines a person's beliefs of having appropriate skills, resources and support necessary to manage a situation. Keiskamma's main purpose is to combat HIV; they spread knowledge and provide services to meet people's needs. The interviewee's felt they could manage their situation with the help of health services and social support. This showed in the confidence expressed whilst talking about the subject. The third component is meaningfulness which focuses on that desired outcomes are worth aiming for and working towards. The interviewees expressed sense of meaningfulness because the number of deaths due to HIV had declined since the organization opened so they believed in what they were a part of. What I noticed in the narratives was that when people were newly diagnosed and didn't have much knowledge about HIV they had more disastrous thoughts about their future life and when they got more knowledge about HIV and how to live with it they gained more confidence in life. The VHW job was to create hope and make the newly infected persons understand that through medication and healthy living habits you can get well again. A VHW says: *"By that time people were very sick and I was encouraging them that this was not the end of life because I'm also HIV positive."* Spreading knowledge about how to cope with HIV was an important tool in gaining hope among newly infected.

Stigma according to Goffman (1963:147) means making a judgment about an issue that is significantly untrue. The vast majority of the population in the village of Hamburg is black and when the white South African medical doctor moved to Hamburg in the beginning of year 2000 people pointed her out as the reason behind the many deaths. A respondent said:

"At the time Dr Baker came here there were so many people that were dying in the village. So the people thought that there's a doctor coming from another country and is sprinkling HIV here. That is why so many people are dying. So they myth, they myth all the time." Some of the local people in the rural villages believe in witchcraft and magic so when the South African Carol moved there, myths spread to explain the HIV spread in the village. Negative attitudes towards HIV are stimulated by local or cultural beliefs about the illness and its causes (Castro and Farmer 2005; Gilbert and Walker 2010 in Ogunmefon *et al* 2011 p86-87)

I want to make a knowledge comparison with the statistics that emerged in Brady (2012) survey where questionnaires were distributed to 950 households in the 47 villages Keiskamma tries to reach out to. It revealed that a number of misconceptions regarding HIV transmission were found, 47% of participants believed that mosquitoes could transmit HIV, and 34% of participants believed that HIV could be spread by witchcraft. These are high percentages and with that I want to emphasize that there is an unequal knowledge level between the persons I interviewed, that had an active role in the organization and the people that lives far from Keiskamma.

6.5 Belonging

Under this heading I do not only refer to social belonging but also professional belonging. What it means to belong somewhere professionally in a village where the unemployment rate is 76.5%. The ones who have jobs are economically independent, so having a job is an important factor to wellbeing. It generates income and many of the employees at Keiskamma are HIV positive and their job is to help other people living with HIV which was experienced as a fulfilling job. Some of the respondents said:

“As I'm working here, that makes me strong because if I'm staying in my house and I'm not working it would be devastating. But now I'm working here and that makes me strong because I am a talkative person. I'm not keeping it in. I'm keeping it out. If I have a problem I will share it...” For this respondent her job was a meaningful way to spend her time. Seeing colleagues and talking to them on a daily basis gave her social and emotional outlet. Professional belonging reduces stress factors such as food for her children, paying expenditures and uncertainty about the future. Further it increases in an indirectly way a person's sense of coherence since one then can predict a secure future for oneself and the family.

The employment opportunities created by Keiskamma has had a vital effect on some of the employee's life.

“Before it was a hard time for me when I lost my husband because I wasn't working. I was dependent on him. So after my husband died they offered me a job so now I am able to put something on the table for my children, even for my family. I'm a breadwinner of my family because of the Keiskamma Trust so it has helped a lot. Although I'm getting less money but God help me all the time.” A breadwinner is someone who provides money or is the source of others survival.

Belonging to support groups was by many of the respondents indicated as valuable. Through the support from the support groups many of the respondents dared to speak out about their status to their family and friends.

“I work in support groups and I used to tell them about my status. Maybe that is why I am alive, because of the support I was given from my colleagues in Treatment Action Campaign. As from 2010 I decided to tell my family, all of them. So they know now.”

“When you're going to the support groups you have friends there and they are going to support you” The network created in support groups is of importance to how the participants cope with their life as HIV positive.

An interviewee appreciated the help and advice she had got from the support group leader. Having a person in her network who have experience and knowledge about what was unknown to her helped her in her process of accepting and acting upon HIV.

“The support group leader advised me and told me what to do, that I must accept that I am HIV positive, she is the one who gave me hope. I firstly didn't accept it but I know I have it and she told me to do this, this and this. She told me to contact her if I had any problems. She is the one who advised me to tell other people about my status like my auntie and grandmother. She helped me a lot”

The leader of the support group said:

“They appreciate it. Every time they want to sit with me... They want to come and visit me all the time. Some they phone me if they have problems. Even during the night.”

6.6 Analysis of Belonging

I noticed that the South African culture was very family friendly and appreciated socializing. Many of the interviewees said for instance that the support groups and being able to talk openly about the disease with friends and family was a reason to why they had survived. Belonging to Keiskamma, support groups and their family were indicators that relate to coping (Lundin *et al* 2009:112). The sense of belonging is very important for wellbeing. It higher manageability because then you know you have support in case you would need it.

Professional belonging somewhere increase the concerned family's life standard. The ones hired, which mostly are woman, are provided with salary and this independence factor was appreciated by most staff members. The interviewee's I met had built up their confidence through the organization; I could understand that by processing the observations and talking to them. For instance the people employed at Keiskamma had high confidence in being open about their status. Often in campaigns one of the employed women would stand up and talk about her life story as HIV positive.

Belonging to a family, income generating profession, support group and friends are key factors as coping mechanisms (Lundin *et al* 2009) and higher sense of coherence among the respondent's (Antonovsky 2005).

6.7 Network

In cases where the interviewee had children or others they needed to look after and take care of, the wish of becoming stronger and coping from the virus increased. The feeling of responsibility

motivated the interviewees to recover and become strong so they could take care of their children. One of the respondents was trying to live healthy so that she could stay strong for the sake of her children.

“I'm not doing those things because I'm thinking of my kids firstly. I want to see my kids grow bigger and bigger.” With things she means intake of alcohol and unprotected sex.

Also in this case the responsibility of parenthood is a significant factor to why the respondent felt she needed to recover mentally and focus on what is important. Children in these cases have been the motivation to cope.

“I was angry when I found out that I had HIV but because I was pregnant I had to focus on my pregnancy so that my baby would be fine. The nurses advised me that I must not have stress, yes I tried my all to stop thinking about it because I was pregnant and had to look after the pregnancy”

Having children that are grown up increases the sense of coherence since then you know that your children can manage without you. A respondent said that he does not worry about his children and he was happy that they were grown up now that he has HIV:

“I feel comfortable telling my children about my status because they are grown up. They must know”

Important people in the respondents surrounding has been meaningful when it comes to accepting the HIV diagnose and to see a future life. Dr. Baker, who started the organization has been an influential person and has affected many people's lives in a positive way. This is what former patients say:

“I don't think people would have survived during that time if it was not for Dr. Baker. When Dr. Baker sees the patient she does everything to help the patient. Without the clinic in Keiskamma it would not be good for me. People they know that if Dr. Baker is at the clinic they are going to be healed... But if we don't have this Keiskamma maybe there are lots of people dying.”

Other respondents said:

“The rate of death is not so high in Hamburg because we got Dr. Baker.”

“I met Dr. Baker and she persuaded me that “you are not alone to do this” that's when I thought; No it's going to be fine.” Faith and trust in the competence of the medical doctor has brought hope to the individuals. Knowing the doctor and having her in their social community network had saved many ill people's lives.

Another aspect that increased the respondent's coping ability and sense of coherence was supportive people in their surroundings. It is not only about the support but also that they had told people and didn't have to live hiding secrets.

"I'm feeling good because I'm healthy and my mother, family, colleagues and my pastor are supporting me" It was meaningful for the interviewees to have gained support from their family and relatives.

*"Yoo I think I would not be here, maybe I would be dead because I have two supporters here. People like *** and other people, they supported me and that's why I survived"* Significant people in a person's life that supported them in their illness was of great importance.

6.8 Analysis of Network

The village of Hamburg, as most other rural areas in South Africa was influenced by a strong collective way of living. The collective is attributed great importance since it stands for security and protection. Network was brought up as a very important factor in the lives of the interviewees. Socializing and being able to talk about their lives and disease was considered very important. In the book *Social handling och sociala relationer* the authors Edling and Rydgren (2007) highlights the subject social network. The study of social network analyzes relationships between individuals, organizations and nations. It is of interest to find out how relationships are created, how they affect people's action and decisions. Social networking is important because it is a flow of information channels, sources of social pressure, sources of social encouragement and support. This means that social networks affect people's behavior in a direct and often decisive way (Edling and Rydgren 2007:281). Many mentioned the contact with Dr. Baker as vital, having access to a medical expert saved lives since she was the only doctor in the 47 villages. The positive aspect of social network is that it can motivate one to cope and increase sense of coherence. Feeling responsibility for children as a parent were brought up by the respondents as a factor that motivated them to cope. On the other hand social network that stigmatizes has high demands or pressure someone can lower sense of coherence.

In relation to the interviewee's many respondents mentioned that it was important to their wellbeing to have social network because they needed air their feelings out and work through their experiences and feelings by talking about it. Knowing that they were accepted the way they are and that they are not alone in their situation made them stronger. Social network through support groups works as information channel sources for encouragement and support, their function was valuable for the participants. Goffman (1963: 88, 28) also supports this; he writes that when people with the

same stigma socialize, the stigma disappears. The regular meetings create friendships ties and affinity. The interviewees said that they had made many new friends through the support groups and friendship is a strong relationship which means that it contains a temporal and emotional commitment.

Edling and Rydgren (2007: 288-289) and Goffman (1963: 31) writes that it is a fact that people tend to be in relationships with people who are similar to themselves in different ways. People's social networks are relatively homogeneous in terms of categories such as social class, religion and ethnicity. This may be because one is born into a certain social class or religion but research also shows that the companionship individuals themselves establish are often to people in a similar life situation for example rich people establish contact with other rich people. The authors call this homofili. In relation to the social links established among the participants of the support groups, colleagues and patients in the Keiskamma Trust the superior gravity has been HIV. People regardless of color, religion and social status can be infected with HIV but the common factor the people in the support groups has is living with HIV. Homofili can also be negative since it can have an excluding power. It can lead to social segregation which means that there is no relation and such situation can aggravate the rise of uncertainty between people from different groups. This could in the worst scenario imply that HIV positive loses confidence towards HIV negative. There for integrated homofili is to prefer since then the prejudice and stereotypes reduces and mutual trust rises. In terms of support groups everyone was welcome, people who had HIV and others who came there to get information or support a relative.

6.9 People's view of them

Through observations and informal conversations with young people in the village and in conversations with my supervisor it was apparent that young people get tested for HIV to a very small extent. Adolescents did not dare to go to the clinic because the village is small and has a small population. Everyone knew each other so it was common that patients knew nurses private. Adolescents were afraid of rumors and avoided going to the clinic. The young people who did test themselves were the ones who became very ill and had to seek medical help.

Many hospitals complained that the stocks of medicine ended before new arrivals came. Not taking the ARV as prescribed is dangerous for the patients. Letting this happen over and over again showed that the government did not prioritize this issue. Today, the government pays for HIV treatment but before people were supposed to buy the treatment themselves with the money they gained through the disability grant. The grant is time limited so people did not see use in buying the medication

since they would in 6 months not be able to buy it any more.

“When you went to the public hospital they used to tell us that there is no ARV and I think they put our life in danger. Our government give people 6 months disability grant that's why people decided not to take the treatment because of poverty.” To politically not prioritize a disease that has fatal consequences for the sick is according to me stigmatizing for those affected. The life value was politically lowered since the government did not economically supply with what needed. I think that the stigma has lessened now when the government is supplying its population with ARV for free. I relate this to the high frequency, 70% of testing that is today according to Brady's (2012) survey.

It is not easy for people living with HIV to tell other people about their status. Some are afraid of e.g. being treated differently, others are afraid of being left by partners. It was the interviewees perceived views of what people thought of them that made them unable to disclose of their diagnosis. Some quotes below describe this:

“I know other people that are afraid to tell other people about their status”

*“As from the years 2003, 2004, 2005, 2006, 2007, 2008, 2009 I didn't tell my family but I used to tell people outside. Because I'm not from here, I'm from *** so I used to tell people I didn't know and they gave me support.”*

“At the time when I was diagnosed the first thing I was thinking about was that my friends might dislike me.” To not dare talk openly about an issue means that the issue itself is stigmatizing so no one want to be related to it.

When someone got HIV diagnosis many relatives thought it was a death sentence. A respondent says:

“When the people saw me in the hospital car they shshsh they were gossiping about: “oh there is someone that is very sick in that house.” When they saw me they thought I would die because when people get HIV they don't accept their status so they do funny things like drinking and sleepover, you see.” The respondent means that the diagnosed person does things that you should not do when you have HIV and thus hasten their death.

“In the clinic I asked about where my rings, earrings and watch were and they said my mum had taken my things home. Then I took the phone and called my home and said “where's the things you took from me?” and she said “oh it's you” Because they thought I was going to die even my mum.” Since many victims have been harvested by HIV in South Africa, it was taken for granted that

anyone diagnosed would die of the disease.

HIV is related to misbehavior like having many sexual partners and alcohol consumption. There for bad rumors easily occur about someone who has HIV. *“I decided to not tell my family at that time because I used to hear when they were talking about someone else”* I later asked how the family reacted when she decided to tell them and the respondent said:

“Some just cried, you know. But for me I was fine and I was relieved. The respondent told her family several years after she herself found out about her status because she was afraid of being judged and stigmatized. The family became very worried and thought of the worst but she calmed them down.

6.10 **Analysis of people’s view of them**

I noticed a difference between the respondents. The respondents that either lived close to the organization or worked there tended to more easily disclose their status to relatives and friends. Respondents that lived in the villages far away from the organization and other medical facilities tended to keep their status to themselves. I believe the difference lies in the surroundings perception of HIV infection. People that lived close to the organization were more exposed to the knowledge and discussions about HIV. They had closer distance to support and help, these respondents told their family and friends in a few years of time or immediately. People in the far away villages had distance issues to health care, support groups etc. whereas the disease was not as explicit. The two respondents I interviewed that lived in the far away villages disclosed their status to as few persons as possible and did not plan to tell more people. An example: *“It was me who knew I was HIV positive and my mum only. No one knew. I don't tell the people.”* This respondent did not work or live near the organization and she wanted to keep her status a secret, she did not tell her boyfriend. It can be difficult to talk openly about the subject and people who carry the virus keep it a secret due to fear of being excluded from family, partner, friends and neighbors (Ogunmefon 2011:91 and Simbayi *et al.* 2007).

Some of the interviewees said that their families thought they would die when they found out about their status. Their family cried and became very sad and worried. The fact that HIV has claimed millions of victims in South Africa has resulted in that great fear for the virus has been created. This affects the surrounding people’s image of the ill person. Goffman (1963:14) writes about the stigma created. He says that the person who is afflicted with a stigma is not fully human. Based on this premise, we will take discriminatory measures whereby we effectively but often unintentionally reduces the person's capabilities. Thereby we build a theory to explain his inferiority and convince ourselves and others of the danger he represents, and this we rationalize. I relate this to the fact that

people who are HIV positive are suspected and accused of promiscuity and alcohol consumption. Hereby the HIV positive person is treated on the basis of the stigma and there for discriminated. This takes place by rumor spreading about bad behavior. To avoid all this some people choose to keep their status a secret because they were afraid of being treated differently.

As mentioned earlier adolescents did not go to the clinic for HIV testing because the village is small and has a small population. Adolescents did not want to be associated with rumors of unsafe sex, HIV etc. This was considered a problem because it was difficult to motivate the young people to test themselves. Simbayi *et al* (2007) writes that people in their study that were unaware of their HIV status reported that stigma influenced their decision not to get tested. This interferes with HIV prevention, diagnosis, and treatment. According to UNAIDS (2009) the incidence of HIV among young women aged 15-24 is about three times higher than among men of similar age. This was explained by the locals that men undergo circumcision, and that the procedure reduces men's risk of becoming infected with HIV.

6.11 Frustration

Goffman (1973:28) writes that stigma in relation to ill-health presumes that illness has occurred as a result of misbehavior, rationalizing the privilege of the well over the ill. In conversation with villagers it emerged that people overweight are considered beautiful, well off and healthy in the rural areas of South Africa. Many of the respondent mentioned weight loss as a period of when they felt observed and uncomfortable. It is not obvious what is stigma but below is quotes that I see as stigma related.

“Sometimes I feel like “oh my God why did you give me this” Sometimes when I saw beautiful people, before I got sick I was too cute. So I said to myself “oh no my neck is to long no, my legs are too thin so I couldn't ware tight clothes anymore. Oh my God sometimes I was crying but now those days are over.”

“I started to take ARV's because I became thinner and thinner. Now I am fine. But I used to be stressed and depressed because my clothes were too big for me and people spoke bad things about me even those who knew I had been living with HIV for many years. Communities still discriminate people who are living with HIV in different ways.”

“It is not nice to become HIV positive because they used to take you for granted and lowered your dignity. When you become thin they told you that you have sex and drink alcohol. They are

judgmental. They don't want to hear what you are saying as a person who is living with HIV.” As the quotes above explain, it is not easy to be thinner than ideal because then people suspect you have HIV and associate that with bad lifestyle habits. Weight loss aroused negative feelings amongst the respondents.

Another situation that can be frustrating for the one concerned is being treated differently by close ones. Rumor spread was common and was experienced as difficult because people changed the perception of the one concerned.

“You know people likes to gossip. You can tell someone you trust but that one can tell someone, and that one tells the other one. And when your boyfriend knows that, then you can see that things change”

Condom use is not appreciated amongst especially the male population even though the rates of HIV infections are very high. The respondent told me about her personal relationships, that when men got tired of the condom they left the relationship.

“Even if the boy also is HIV positive. He don't want to do the things we are supposed to do like condom use because they don't want to use condom. So he just runs away and goes and infects those who don't know their status. That is why it is not easy” The issue about men not being willing to use condom was raised by women. Men used to say things like: who wants to eat a banana with the peel on or who wants to eat a wrapped candy-bar?

Some of the respondents expressed frustration when finding out about their status. They wondered who had infected them another became angry at their partners because they suspected them of infection spread.

“Yes but I was afraid when I got it. I blamed my boyfriend and I was angry” The respondent was afraid when being diagnosed but she blamed her boyfriend and was angry at him.

6.12 **Analysis of frustration**

Frustration can undermine coping because frustration is negative emotions that give focus to the difficulties of living with HIV. The frustration that emerged was that they wanted to know who had infected them. It was hard to accept that they would live with this virus for the rest of their life. Frustration also arise when HIV positive are treated differently and spoken ill of. Goffman (1963:28) writes that in social situations where we know or notice that a person has a stigma, the risk is that we resort to categorizations that are significantly untrue. This usually discredits the concerned person. That might be why many respondents considered the weight loss period as

difficult since that is when people observed, started gossiping and spread rumors. Goffman (1963:77) writes that the rumors function is social control in such way that people wants to keep track of the person. Further on I think the way South Africa has politically portrayed the HIV epidemic has led to stigma problems. The fact that the government in the initial phase failed to provide the population with knowledge and medication, especially in the rural areas has influenced people's view of HIV. The same respondent said that it had happened to several people including herself that when they went to the clinic to get medication the stocks of ARV's had run out. This indicates how seriously the state neglects HIV disease. Lack of health care, doctors and medicine was remarkably worse in rural villages. Brady (2012) writes that a structural issue that is relevant to the lack of medical doctors in the rural areas of South Africa is that of the 1200 doctors South Africa trains each year, 50% go overseas and 25% work in the private sector. Of the 25% who remain in the public health sector, less than 3% work in rural areas. The inequitable distribution of health care professionals results in huge shortages in rural health facilities. A solution to this is to increase interest in working on these vulnerable areas by higher salaries or other benefits that the state should stand for.

Another problem that was raised by women was that men refused condom even though they knew the risk of infection. Women who worked in the organization were economically independent and could therefore refuse sex without a condom. People that have knowledge about HIV and an income are thus better equipped to protect themselves against the virus (UNAIDS, 2009: 30, 35). They were very strong and had strong principles that were clearly expressed. However, I believe that women without a profession, living in the patriarchal family system in the villages do not have the same conditions. According to UNAIDS (2009) women in the rural areas of South Africa are usually economically dependent on their husband/boyfriend and have it difficult to negotiate safe sex.

These different examples brought up: feeling observed, rumors, not having enough medication may create frustration among HIV positive and are factors that can threat sense of coherence.

6.13 **Emotions during the time of diagnosis**

In order to describe the feelings that arose when finding out their status these terms were used: sadness, anger, fear, surprised and shock.

"I was afraid"

"I was shocked because it was me, my husband and one of my children so I was shocked, you know especially for my child. I still haven't accepted it for my child" Two more family members were also sick and that came as a shock.

“I was feeling dizziness and I was not good, couldn't remember anything. I was so confused at the time. I was shivering” The interviewee was very ill when she came to the hospital so during the time of HIV testing she felt very sick.

On the question “how do you experience your life at present” almost all of the respondents said they felt exactly the way they felt before they became ill. They felt healthy and strong. Most of them had lived with HIV for years and had the disease under control by varied meals, medication (in the cases needed) and living with the restrictions that HIV implies.

6.14 **Analysis of emotions during the time of diagnosis**

Being diagnosed did not necessarily increase sense of coherence. It was relieving for the respondents to find out what was wrong and why they felt ill but at the same time it was initially difficult to accept that they would live with the virus for the rest of their life. The respondent’s sense of coherence was lowered during the time of diagnosis and during the time it took them to accept the fact that they had the virus. At the time I interviewed them; most had been living with HIV for years and then showed high sense of coherence (Antonovsky 2005). In general an optimistic spirit was expressed; the respondents saw opportunities and a functional life ahead of them.

The study made by Simbayi *et al* (2007) examined the occurrence of discrimination experiences and internalized stigmas. His study shows that discrimination experiences and internalized stigmas were common among individuals living with HIV/AIDS in Cape Town. 30% of the respondents in the study admitted feeling humiliated of oneself and guilty related to their AIDS status. In my study I asked about feelings and emotions before the diagnosis, during the time of diagnosis and afterwards. Common words used to describe feelings were sadness, anger, fear, surprise and shock. No one mentioned feeling guilt, shame and did not to express internalized stigma to a wider extent. My study does there for not confirm the results indicated in Simbayi *et al* (2007).

7. **Concluding Discussion**

The aim of this study was to increase my understanding of how people experience living with HIV in South Africa. Through a qualitative approach my objective was to explore how six South African HIV-diagnosed persons experience the social and emotional consequences of being infected and how the support structure provided by the non-governmental organization Keiskamma affect their everyday lives. The answer to these questions depends on the purpose for which respondents went to the organization. Four of the interviewee’s went there for income generating purpose. The other respondents went there for HIV and PTMCT training. As the organization provided with food parcels, transport, HIV campaigns, VHW, PMTCT training, OVC centers, job opportunities and

youth camps the respondents were affected by the organization in a direct or indirect way to the extent they chose to use the services. Of what emerged in the interviews, observations and meeting the respondents an optimistic spirit was expressed. The majority of those I interviewed had been diagnosed for several years, and they showed that the old views on HIV had loosened up and thereby also their view of themselves. Common words used to describe feelings at the time of diagnosis were sadness, anger, fear, surprise and shock. It took time for the respondents to accept that they would live with the virus but as time went by with medication, HIV education and encouragement from support groups they gained control over their situation. Common words used to describe feelings at present were healthy, good, normal, fine and strong.

Socially, most of the respondents said they had more friends than before the diagnosis and this depended on the contacts made in the support groups. Initially they were afraid of disclosing their status to family and friends in fear of being treated differently or excluded but they were not in most cases. In two cases partners had chosen to leave the relationship because of the virus.

7.1 Discussion

The former government of South Africa denied the HIV epidemic in the country and this has in the long term caused great consequences for people who are currently living with HIV / AIDS. The governments neglect and denial has largely resulted in that many lives have been lost that could have been saved from the virus if they had received medication (ARV's) in time. They did not supply education and information about prevention. This is still severely deficient in the rural areas. The previous government carries a large debt to the society and why HIV is a stigmatized disease, especially in the rural areas as it was considered incurable.

Before the organization Keiskamma began its efforts in the village of Hamburg HIV was taking many people's life. The organization was initiated by Dr. Baker because she found that there was a great need. The organization became a meeting point for people in the village who wanted to bring changes to their situation. Through collected donations job opportunities were created and they were gaining salary for the vital work they did and are doing. Now one decennium later I met and interviewed some of the employees and other users of the service offered at Keiskamma. After analyzing collected material six recurring themes were identified: faith, knowledge, network, belonging, people's view of them, frustration and emotions during the time of diagnosis. The discussion below summarizes the results in more detail.

The respondents were grateful towards God for what they had and they appreciated the Keiskamma organization and its founder Dr. Baker. The trials and tribulations the respondents endured were related to Gods plan, they had trust and acceptance of what God gave them. Religious beliefs

contributed to their resilience in coping with HIV and other difficulties in their lives (Perry *et al* 2008). Knowledge was a significant factor for higher sense of coherence and confidence. When the respondents were newly diagnosed they had disastrous thoughts about their future life but as they gained more knowledge aspirations and hope of a healthy life became reality since they got to know how to maintain good health and living. They all mentioned the same limitations in their life as HIV positive, which is alcohol restriction and protected sex.

Other recurring themes that were brought up in the narratives were importance of socializing, social network, family and children. The collective was attributed great importance in their lives. For instance the respondents that had children felt motivated to recover from their morbidity so that they could take care of their children, they felt responsibility towards them. Socializing with friends and being able to talk about their lives and disease was considered the best way to air out feelings, thoughts and emotions. Edling and Rydgren (2007 p 281) writes that social networking is important because it is a flow of information channels, sources of social pressure, sources of social encouragement and support. The support group was a good channel of information and the participants boosted each other with encouragement and support to e. g. disclose their status and not live in secret.

The unemployment rate is 76.5%, usual income source is government grant (37%) and pension (37%) this amount is distributed on the household so people live in severe poverty (Keiskamma Baseline Survey 2012). There for an important factor that the respondents brought up was professional belonging, the ones who have jobs are economically independent and have better prospects. It reduces stress factors such as food for their children, paying expenditures and uncertainty about the future. Professional belonging increases in an indirect way a person's sense of coherence since one then can predict a secure future for oneself and the family. According to research it is difficult for women to negotiate safe sex, but when women are financially independent and has knowledge about HIV they then have better prospects (UNAIDS 2009) and my study confirmed this.

When it came to the surrounding people's view of the respondents, whereas the stigma theory is relevant, a difference was noticed. The respondents that either lived close to the organization or worked there tended to more easily disclose their status to relatives and friends. Respondents that lived in the villages far away from the organization and other medical facilities tended to keep their status to themselves. I believe the difference lies in the surroundings perception of HIV infection. People that lived close to the organization were more exposed to the knowledge and discussions about HIV. They had closer distance to support and help. People in the far away villages had distance issues to health care, support groups etc. whereas the disease was not as explicit. People who carry the virus keep it a secret due to fear of being excluded from family, partner, friends and

neighbors (Ogunmefon 2011: 91 and Simbayi *et al.* 2007). In the Keiskamma Baseline Survey 2012 it emerged that the knowledge about HIV was very poor in the 47 villages surrounding the organization and I relate this to above conclusion.

Issues brought up by the respondents that gave them negative feelings were: feeling observed, rumors spreading, incidents when not being provided necessary medications and periods of weight loss. These issues were collected under the theme frustration since it aroused negative feelings that may threaten sense of coherence and coping ability. Usual things to accuse a HIV positive with are having multiple sexual partners and alcohol abuse. To be overweight represented health, beauty and fortune there for weight loss was a difficult period in the interviewee's life their confidence lowered and people suspected them of being ill in HIV.

The last theme was emotions and common words to describe feeling at present were strong, healthy, good, fine and normal. For the people that were active in Keiskamma by working there, used services, knew people the prospects were good. It was interesting to see the importance of Keiskamma's work, as it has led to fewer deaths and less stigma. Further the village is distant from modernity and technology, the international contacts they have broadens their horizons to other continents and ways of living.

Today, the situation is better than before in Hamburg but what slows their efforts to improve their situation is structural, economical, political and scarce resource obstacles. The ultimate solution to HIV/AIDS does not lie in the hands of people living with HIV/AIDS. Structural interventions are needed to change the social climate of AIDS. The government must give attention to the many rural areas in South Africa and provide them with their human rights such as necessary medical health care. Except from providing the public with free ARV's, they have not focused on that everyone should have access to health facilities with medical expertise. Another reason to the lack of medical doctors in the rural areas of South Africa is that of the 1200 doctors South Africa trains each year, 50% go overseas and 25% work in the private sector. Of the 25% who remain in the public health sector, less than 3% work in rural areas. The inequitable distribution of health care professionals results in huge shortages in rural health facilities (Keiskamma Baseline Survey 2012). A solution to this is to increase interest in working on these vulnerable areas by higher salaries or other benefits that the state should stand for. In Keiskamma it is the donors that pay the salaries of the employees, it should have been the government but they will not take responsibility. Through advocacy the Keiskamma tries to create a cooperation with the government. London *et al* (2012) writes that advocacy is an activity that includes an individual or group who aims to influence public policies. In this case influencing health resource allocation decisions within politics. This is a slow process

because the government was not showing much interest. London *et al* (2012) writes that within the health sector in South Africa, the socio economic rights for the population is severely unequal. It has left the most marginalized people in society particularly vulnerable. In South Africa corruption is widespread. Corruption always strikes the poor and vulnerable people since they do not have much political influence, there for it is difficult for them to create structural changes that would improve their situation.

When it comes to receiving donations it is not friction free. Dr. Brady, Keiskamma representative said that donors are necessary for their work and highly appreciated but the backside is that donors most often set the agenda of what is important, what the focus will be and what work that needs to be done. This result in that organizations do things that are not a priority but the problem is that they can only get funded for certain things. Donors know this but they help in such way they think is most beneficial. I find this problematic because good intentions do not always lead to good outcomes. Experienced social problems differ from one country to another because it is often structural, political, economic and other factors that together shape defects at micro level. This can be difficult for outsiders to see because they do not live in that environment. People in communities have the capacity to identify problems and solutions since they are participants of the every-day life (Cotrell 1983 in Minkler *et al* 2008: 293). Therefore, organizations that receive assistance should get the chance to identify and formulate their own problems and be supported in that. For external agents to formulate new goals changes focus on the real necessary targets that need to be addressed. Money from donors should be spent on getting people out of poverty and not addressing the symptoms of poverty.

This study has highlighted different aspects of HIV in rural South Africa. It has brought up a discussion about the structural and governmental neglect when it comes to the people living in the rural areas. Of what I had read about the subject before travelling to Hamburg, I expected it to be much worse than it actually was. Significant progress has been made in Hamburg in terms of stigma and access to ARV's. The problem is that the progress is unequally distributed. For instance in the capital, Capetown it was much less stigma and access to help was more available, in comparison to Hamburg. In villages where there were organizations, help was available and stigma was relatively low. As to the villages that has gained no attention there are still serious problems. Today there is no lack of knowledge about HIV but rather the knowledge conducted requires affirmative action that reaches out to all people to improve their quality of life.

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9. Questions for the semi structured interview

Name

Age

Income/how do you fill your day-to-day life?

About the organization

- How did you get in contact with Keiskamma?
- What does Keiskamma help you with/do for you?
- How do you experience the service Keiskamma offers you?
- How do you think your situation would have been if you did not have the support from Keiskamma?

Experience of living with the disease

- When did you get your HIV diagnosis?
- How did you feel before the diagnosis, physically and emotionally?
- Can you tell me about when you got the diagnosis HIV? How did it feel emotionally?
- How do/did you feel after the diagnosis, physically and emotionally?
- How do you experience your life with HIV at present?
- When you found out about your HIV status, who/which people did you feel your could talk to about it?
- How long time passed before you could tell anyone about your HIV status?
- Has it been possible for you to discuss HIV with you family/relatives/friends?
- Has your life changed socially after the diagnosis?

- Do you think your life has been limited by HIV? If so, in what way?
- Do you think you can live a functional life with HIV?
- Is there anything in particular that makes life easier for you? (coping)
- What strengthens you in your life? (coping)
- What would the patients like to be helped with that Keiskamma does not adress?

9.1 A clarification of what used terminology means in the context of my essay

Self-experienced = subjective and personal experience of an issue, in this case HIV. Focus is on the interviewee's opinions, feelings and experiences of living with HIV.

Consequence = in an online dictionary the word consequence was described like this:

"a result or effect of some previous occurrence" (www.thefreedictionary.com). In relation to this thesis I seek to find out the social and emotional consequences of living with HIV.

Social consequences = with this term I seek to find out if the interviewee has had a change of her/his social life after being diagnosed with HIV. Has family members, relatives, friends or neighbors lessened, increased or changed attitudes towards the interviewee? How has the social life namely people surrounding the interviewee reacted to the diagnosis.

Emotional consequences = with this term I seek to find out which feelings were aroused when the interviewee was diagnosed and what feelings that are still gnawing in relation to HIV.

Support structure = relates to what support and help is available for the patients in the Keiskamma organization. There is medical help, activities to take part in such as camps, support group, music, art and dance.

Functional = the definition of functional is contextual, hence mean different things in various social settings. Being functional in this essay means the ability to participate physically in activities like others do e. g. activities such as work and hobbies. Functional in a sense of doing activities one could do before the HIV diagnosis.

Stigma = Goffman (1973 p. 28) writes that being stigmatized is often a result of stereotypical opinions that carry no real facts. Stigma additionally divides a person from the larger society, giving reason for suspicion and hostility towards the individual.

Internalized stigma: involves internalizing society's negative messages about HIV that creates negative thoughts and feelings about oneself. Feelings of guilt, self-blame and shame (Simbayi *et al.* 2007).