INVESTIGATING HOW THE STIGMA IS PERCEIVED AND HOW IT CAN BE REDUCED

HIV/AIDS-RELATED STIGMA ON WOMEN IN KWAZULU-NATAL
MASTER’S THESIS:

‘HIV/AIDS-related stigma on women in Kwazulu-Natal: investigating how the stigma is perceived and how it can be reduced’.

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ABSTRACT

This thesis explores the HIV/AIDS-related stigma on women in the cultural context of KwaZulu-Natal. The HIV prevalence rates are very high in this province of South Africa and the stigma stands in the way of reducing these rates. The research is conducted at Bobbi Bear, an organization in the town of Amanzimtoti. Bobbi Bear’s objective is to rescue and help sexually abused children. Furthermore, Bobbi Bear aims to create awareness and knowledge about HIV/AIDS by providing education, trainings and support groups for women and children. Qualitative research was conducted to gain the insights and perspectives on the stigma of various professional actors that are involved with Bobbi Bear. HIV/AIDS-related stigma, interventions to reduce the stigma and gender inequality were important concepts in this thesis. By building from the theoretical discussions and perspectives on these concepts, this thesis aims to investigate the HIV/AIDS-related stigma on women and to come up with methods that can help to reduce the stigma on women.
FOREWORD

As I am writing this personal note, I can look back on a rather successful period. I was able to conduct my research in my favourite country on the topic that I find extremely interesting. Even though I have experienced struggles in my fieldwork, due to the sensitivity of the topic, the time I spent in South Africa has been wonderful. I cannot describe how valuable the time I spent at Bobbi Bear has been, how much I learnt, not only about my research topic, but also about life in general.

I am very satisfied with the results of my research. I feel privileged to have talked for hours with people about the stigma on HIV/AIDS, even though it is such a sensitive topic to talk about for them. They provided me with so much information and so many touching stories and I cannot emphasize enough how valuable these people were for my research.

Furthermore, there are some people I would like to thank. First of all, my supervisor Jacobijn Olthoff. Thank you for your guidance and critical comments. You helped me to get the best out of myself. Secondly, I want to thank all of my research participants. Thank you so much, I highly value your opinions and I am very thankful that you shared your stories with me. Also, a special thank you to everyone at Bobbi Bear and in particular Eureka Olivier. Thank you so much for everything you did for me. You are all heroes and Eureka, I think you really deserve a crown. Finally, I want to express my gratitude to a very special person. The person who, to me and probably many others, is a hero. Jackie Branfield, thank you for helping with my research, for making me feel so welcome, for your continuous strength and power to fight for the children. You gave me inspiration for a lifetime.

Kayleigh Boerjan
List of Abbreviations

ACDP  African Christian Democratic Party
AIDS  Acquired Immune Deficiency Syndrome
ARV   Antiretroviral (drug)
HIV   Human Immunodeficiency Virus
MDG   Millennium Development Goal
NGO   Non-Governmental Organization
PEP   Post Exposure Prophylaxis
SAP   Structural Adjustment Programme
TB    Tuberculosis
UNAIDS Joint United Nations Programme on HIV/AIDS
UNDP  United Nations Development Programme

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1. **INTRODUCTION**

After months of gaining theoretical knowledge about development issues, the time arrived to put this knowledge into practice. In July, I left for the field to conduct my graduate research. I decided to focus my research on HIV/AIDS-related stigma, because I feel that the stigma is one of the largest barriers in overcoming HIV/AIDS. I went to South Africa to conduct my research at Bobbi Bear, a local NGO nearby Durban, in the province of KwaZulu-Natal. Bobbi Bear aims to help children who are sexually abused to cope with this trauma (Bobbi Bear 2012). The staff members use a stuffed animal, Bobbi Bear, to obtain forensic facts and evidence to assist the justice process and to increase awareness about sexual abuse and HIV/AIDS within local communities. Therefore, the Bobbi Bear has become a symbol against sexual abuse and HIV/AIDS in South Africa (Bobbi Bear 2012).

South Africa has the largest number of HIV positive people in the world (Overseas Development Institute 2007). As elsewhere in Africa, there are many economic, social and political problems related to HIV/AIDS. One of the major side problems of HIV/AIDS is stigmatization. Stigmatization can occur in different contexts, but in this research, I focus on HIV/AIDS-related stigmatization. Stigmatization is a very serious problem, especially in South Africa, where HIV/AIDS remains a taboo subject (Ferreira 2004:5). The prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS has severe consequences. HIV positive people are ignored by their family, friends and the wider community, there is poor treatment in healthcare and it leads to psychological damage (Ferreira 2004; Poku 2005: 74-75). Because of the damaging effects and barriers that HIV/AIDS-related stigma produces, I decided to focus my research on the manifestation and consequences of the HIV/AIDS-related stigma and possible interventions to reduce the stigma in the communities where Bobbi Bear operates, thus, in the cultural context of KwaZulu-Natal. In particular, the purpose of my fieldwork is to investigate how the actors involved with Bobbi Bear perceive stigmatization in the context of HIV/AIDS and how these actors think that the stigma can be reduced. I decided to focus on stigmas carried by women as the topic of my research. One of the reasons why I choose to focus on women is that in the context of HIV/AIDS in South Africa, women are often the victim of stigmatization. In the context section, I will explain more extensively on why I chose women as the victims of stigmatization for my research.

This research has scientific relevance in that it contributes to the on-going debates on stigmatization and HIV/AIDS. My research has scientific relevance on multiple levels. First of all, there are many authors who address the problem of HIV/AIDS-related stigmatization in their books and articles. The complexity of the problem has led to difficulties and disagreement about how to perceive stigmatization. The manifestation of the HIV/AIDS-related stigma varies by cultural setting.
(Mahajan et al. 2008: 1-2). With my research, I presented the perception of HIV/AIDS-related stigma based on the various perspectives of actors who are working with HIV positive women that have to face the stigma or who have seen how women are stigmatized in their community. This provided me with an extensive view of the stigma based on various and diverse perspectives. This view is thus based on the local perspective of the problem based on own experiences and thereby contributing to the on-going debate. Secondly, my research is scientifically relevant because it presented the manifestation and impact of HIV/AIDS-related stigma on women in the cultural setting of Kwazulu-Natal, South Africa. Finally, with this research I contributed to the on-going debate on how to reduce the HIV/AIDS-related stigma. I provided an insight on how the stigma can be reduced, based on the diverse perspectives of the actors involved with Bobbi Bear. Because of their own experiences with stigma and with women who actually have to face the stigma, these actors argued how they think the stigma can be reduced. Therefore, this research is contributing to the theoretical debate with a local and varied perspective on interventions to reduce stigma. Overall, my research is scientifically relevant in that it provides a perspective on the HIV/AIDS-related stigma in terms of definition, manifestation and consequences that is based on the knowledge and experiences of the professional actors involved with Bobbi Bear.

This research also has societal relevance. It contributes to the field of international development, because it addresses stigmatization, a major inhibition in reducing the HIV prevalence rates and causing many people who live with HIV to be excluded. With this research, I provided insights into how stigmatization of women in the context of HIV/AIDS in KwaZulu-Natal, South Africa can be addressed. And not only in the context of KwaZulu-Natal, but also in other regions and countries, HIV/AIDS-related stigma is a major problem. The stigma has many consequences, like social exclusion, depression and higher infection rates. By providing a local and varied perspective on the stigmatization of women, insight is given into the causes, manifestation and consequences of the stigma which might contribute to more effective interventions to reduce the stigma.

Thus, with this research, I hope to find out how the HIV/AIDS-related stigma on women is perceived and how it can be reduced. Based on these objectives, I established my main research question and sub questions:

Central question and sub questions:

*How do the actors involved with Bobbi Bear perceive HIV/AIDS-related stigma on women in the communities where Bobbi Bear operates and how do they think the stigma can be reduced?*
Sub questions:
- How do actors involved with Bobbi Bear perceive the stigma on HIV positive women?
- Why are HIV positive women often the victim of stigmatization?
- How does HIV/AIDS-related stigma on women manifests itself in the communities of the actors involved with Bobbi Bear?
- What are the consequences of the HIV/AIDS-related stigma on women?
- How do the actors involved with Bobbi Bear think HIV/AIDS-related stigma on women can be reduced?

In the next chapter, I will provide contextual information about my research location and research topic. Then, in the third chapter, I will discuss the theoretical perspectives of various scientific authors on gender inequality and HIV/AIDS-related stigma. In the fourth chapter I will present the methodology of my research and the methods I used for gaining data. Also, I will reflect on my fieldwork and discuss the limitations of my research. Then, in the fifth chapter, I will present the data I gained during my research. And finally, in the conclusion, I will provide an answer to my research questions.
2. CONTEXT

This chapter provides the contextual information of my research. In the next section I will provide background information of my research location. In the second section, I will elaborate on why I choose to focus my research on the HIV/AIDS-related stigma. And in the final section of this chapter, I will explain why I choose to focus on women as the victims of stigmatization in my research.

2.1 RESEARCH LOCATION

In this section, I will provide background information about South Africa. This background information will focus on several underlying problems of South Africa’s society, particularly those that are related to HIV/AIDS.

2.1.1 South Africa

South Africa is a middle income country with a population of almost 50 million people. Its current capital is Pretoria. South Africa has nine provinces and the main languages spoken are English and IsiZulu. The key economic sectors are mining services, transport, energy, manufacturing, tourism and agriculture (Republic of South Africa 2010).

In 1948, racial discrimination was formalized in South Africa. The National Party’s dominant strategy was based on apartheid. This strategy covered all aspects of life in South Africa. The continuation of apartheid and the severe punishments of its opponents caused international public opinion to turn against South Africa and made the country into an international outsider. In 1994, apartheid was abolished (UNDP South Africa 2012). Since 1994, a peaceful transition from apartheid to an inclusive and participatory democracy has been taking place (UNDP South Africa Annual Workplan 2011-2012). The changes that took place from 1994 brought possibilities for South Africa to address poverty and inequality. A lot of new policies were put in place to improve the quality of life of South Africa’s inhabitants. But despite the political and socio-economic transformations that took place since 1994, there are still major challenges that South Africa faces. Also, the Apartheid history of South Africa still has a high influence on the current situation of the country. South Africa does have a well-developed infrastructure, private sector and a stable macro-economy, but there is inequality in education regarding access to quality education and there is inequality in access to health care (Republic of South Africa 2010). The unemployment rates are high, 29 percent of South Africa’s population is unemployed and there is a lot of poverty, 34 percent of its population subsists on less than two dollars a day. Development is also negatively affected by crime and corruption.
These are threats to the socio-economic progress and they contribute to poor and unequal service delivery. Also, apartheid’s legacy of structural inequality leads to social marginalization, unemployment and contributes to the high crime rates (CPD South Africa 2010). But one of the most devastating problems in South Africa is the high prevalence of HIV/AIDS. In the second section of this chapter, I will elaborate on HIV/AIDS and its effects on South Africa. But first, I will provide information about the town and the organization where I conducted my research.

2.1.2 Amanzimtoti

I conducted my research in a town called Amanzimtoti. Amanzimtoti is located in the province of KwaZulu-Natal. It is a small coastal town nearby Durban. Legends has it that when the Zulu King Shaka tasted the water in 1828, he said 'Kanti amanza mtoti', meaning 'So, the water is sweet', from where the name of Amanzimtoti originated (Amanzimtoti 2012). Amanzimtoti is a popular tourist destination.

![Map of Amanzimtoti](image)

**Figure 1: Map of Amanzimtoti**

The organization where I conducted my research is called Bobbi Bear. Bobbi Bear is a non-governmental organization with a main policy of rescuing and upholding the rights of sexually abused children. One of Bobbi Bear’s main objectives is to save children from their harmful environment and to minimize their risk of HIV infection. They provide counselling for the child and make sure the child gets all the medical treatment that he or she needs. Furthermore, Bobbi Bear collaborates with and assists the criminal justice system by obtaining forensic facts and evidence by means of the
therapeutic method of the Bobbi Bear. They also support the child and the family during court trials, and make sure the child will be placed in a safe environment. The work of Bobbi Bear is necessary because in South Africa, there is a lot of child abuse going on. When a child is sexually abused, the medical and juridical processes are very traumatizing for a child. Bobbi Bear seeks to diminish further trauma and tries to ensure the rights of a child by intervening in these processes. With rape, the chances of a child being infected with HIV are very high (Bobbi Bear 2012). In KwaZulu-Natal, it is estimated that 40 percent of the people between 15 and 49 years is HIV positive (Republic of South Africa 2012). This is also the perpetrator age group for sexual abuse which puts child victims at a high risk of contracting HIV. Another aim of Bobbi Bear is to increase awareness on HIV/AIDS by providing education and training on the disease to children and in communities (Bobbi Bear 2012). Because of Bobbi Bear’s target group, being children, the direct relation with Bobbi Bear and my research was not very strong. However, as mentioned before, Bobbi Bear also provides education and training on HIV/AIDS in communities and organizes support groups for women where HIV/AIDS is a central topic of discussion. Also, Bobbi Bear counsels young women who are sexually abused and some of the staff members are also qualified pre- and post-test HIV counsellors. Therefore, staff members could provide me with a lot of information about HIV and the stigma. Furthermore, Bobbi Bear helped me with finding research participants. Especially the director and financial director of Bobbi Bear helped me with establishing contacts with people who cooperate with Bobbi Bear and who have to deal with women who have to face the stigma in their daily work. Thus, Bobbi Bear has been a valuable information and network source during my research.

Figure 2 Logo of Bobbi Bear
2.2 WHY FOCUS ON THE HIV/AIDS-RELATED STIGMA?

When the moment arrived that I had to choose a topic for my research, I instantly knew that I wanted to focus on HIV/AIDS. Even though AIDS received a lot of international attention and donor organizations spent large amounts of money on alleviating HIV/AIDS, it is still an epidemic that is out of control. HIV/AIDS causes illness and death, particularly among people between the age of 15 and 50 years of age. These are the most productive people in any society. Because of that, the effects the disease has on this group of people are tremendous. HIV/AIDS does not only have health related consequences, but it also has social and economic consequences. In the beginning, the effects of the disease were only considered as clinically impacting the individual, but over time, it became painfully obvious that the epidemic of HIV/AIDS is not only affecting the health of individuals, but also the welfare and well-being of households, communities and eventually the entire society (Barnett & Whiteside 2002: 3-5).

South Africa has the largest number of HIV positive people in the world. About 30 percent of South Africa’s population is HIV positive and in 2009, an estimated number of 310 000 adults and children died in that year (Overseas Development Institute 2007; UNAIDS 2010). As elsewhere in Africa, there are many economic, social and political problems besides HIV/AIDS. Poverty, unemployment, discrimination, violence and the effects of the SAPs are just a few problems that South Africa has to deal with. It can be argued though that HIV/AIDS is the worst plague torturing South Africa, for it not only has its own devastating effects but it also negatively influences many of the already existing problems in South Africa (Ferreirra 2004). These problems and especially the influence HIV/AIDS has on the entire South African society, makes it difficult for South Africa to reach development targets. South Africa tries to achieve the eight MDGs (Millennium Development Goals) by 2015. The sixth MDG is focused on combatting HIV/AIDS, malaria and other diseases. South African government has intensified the implementation of policies, strategies and programmes aimed at combating HIV and AIDS. One positive effect, and a (small) step towards achieving the sixth MDG, is that it appears that the prevalence of HIV/AIDS is stabilized. Even though, as mentioned before, the HIV/AIDS prevalence levels are still high compared to other African countries (Republic of South Africa 2010). After choosing the general topic for my research, I further specified my research interests. I wanted my research to be relevant, that the results of my research could prove valuable to the world of development. Then I realized that I wanted to focus on why HIV/AIDS is still such a major problem in the world. Especially when so much money is invested in education, treatment, research etcetera, I wanted to find out what the major struggles were in overcoming the epidemic of HIV/AIDS. I knew that education has not reached everyone yet and that people in vulnerable positions are often exposed to the chance of infection. But why did the infection rates not decrease
yet? In some countries the infection rates have declined a little bit and in some countries, like South Africa, the infection rates have stabilized. But there are also countries where the infection rates are still rising (UNAIDS 2010). Then I realized that there is another major inhibition, hidden in the mindsets of people all over the world: the stigma on HIV and AIDS. The stigma is a major inhibition on the efforts to reduce HIV/AIDS and the effects the disease has. UNAIDS has argued that stigma worsens the epidemic and indeed 91 percent of the governments all over the world report that they address stigma and discrimination as cross cutting issues in their national strategies (UNAIDS 2010).

Questions arose that triggered my interest for conducting a research on the stigma: is the stigma preventing people from wanting to get tested for HIV? Are people ignoring information about HIV/AIDS because they think that it does not concern them, or are they afraid to be associated with HIV when they attend informational meetings about HIV? Are people afraid to be associated with HIV when they request safe sex? I figured if I investigated this topic, I would find some answers on why the stigma is such a major inhibition in overcoming HIV/AIDS.

The impact of the stigma on the epidemic and on people living with HIV/AIDS has also been acknowledged in South Africa. The government and development organizations implement strategies to reduce the stigma in their approach to fight HIV/AIDS. They realize that unless something is done about the stigma, HIV/AIDS will never disappear (Republic of South Africa 2010). Prestigious persons have come forward to disclose their own HIV positive status, the South African judge Edwin Cameron stated publicly that he was living with HIV/AIDS. This was in reaction to the death of Gugu Dlamini, who was beaten to death after revealing her status. And Nelson Mandela announced in 2005 that his son had died due to the consequences of AIDS (Nolen 2007: 369-370). Nevertheless, the stigma on HIV/AIDS in South Africa is very high and needs to be addressed more thoroughly. With this research, I hope to contribute to providing answers on how to reduce the blockade that stands in the way of overcoming HIV and AIDS.

2.3 WHY FOCUS ON WOMEN?

In my research, I focused on women as one of the victims of stigmatization. In this section, I will elaborate on the choice to focus on women and on the inequalities that women have to face in South African society and how this is translated into sexual relationships and HIV/AIDS. First of all, I chose to focus on women because research shows they are often the subject of stigmatization (Duffy 2005; Wingood et al. 2008). In some old South African beliefs women are seen as the carriers of HIV/AIDS (Leclerc-Madlala 2002: 89-90). Secondly, HIV prevalence is very high for women. Research showed that the majority of the people living with HIV in sub-Saharan Africa are women. 76 percent of all
HIV-positive women in the world live in South Africa (UNAIDS 2010: 130). Also, it is estimated that there is a ratio of female to male HIV prevalence for those aged between 15 and 49 of 1.5 by 2010 (Statistics South Africa 2010). Thirdly, and most importantly, in South African society, women are often unequal to men. UNAIDS stated that gender inequalities in terms of low socio-economic and political status, unequal access to education and fear of violence contribute to the vulnerability of women and girls being infected with HIV (UNAIDS 2010). South Africa is a highly gender-inequitable country and has a strong patriarchal society. The hegemonic masculinity that prevails in this country mobilizes and legitimates the subordination and control of women. This gender inequity is an important factor in explaining the high occurrence of (sexual) violence against women. South Africa’s rape rates are extremely high, with more than 55,000 rapes reported to the police annually (Jewkes & Morrell 2010: 1-3). Women are seen as inferior to men and this is also the case for sexual relationships. Women are expected to give priority to their partner’s needs and wishes. Often women find that they cannot discuss sex openly with their partners, including asking for condom use, for fear of appearing promiscuous. Also, South Africa is a society where successful manhood is defined by having multiple partners, this leads to men having multiple sexual relationships. Consequently, this leads to women being more vulnerable to HIV infection. Gender issues are recognized as having critical influences on the HIV epidemic in South Africa (Jewkes, Levin & Penn-Kekana 2003: 125-127). The figure below shows in what ways gender-based violence and gender and relationship inequity can place women at risk of HIV infection (Jewkes, Dunkle, Nduna & Shai 2010: 42). There are direct ways in how women are placed at risk of contracting HIV because of gender inequalities, like rape. But there are also indirect ways of how women are placed at risk, for example because of risky sexual behaviour of men.
Therefore, it appears that women in South Africa are more vulnerable to HIV infection due to gender inequalities. During my research, I wanted to find out if women also have to face more HIV/AIDS-related stigma in the context of these inequalities. The results of this can be read in the data analysis chapter. And in the next chapter, the theoretical chapter, I will elaborate more on gender-related inequalities as perceived by various scientific authors.
3. THEORETICAL FRAMEWORK

I divided my theoretical framework in two sections. One section will explore some of the literature that has been written on HIV/AIDS in South Africa and on women’s inequality in the context of HIV/AIDS. In the context chapter I discussed why I chose to focus my research on women. In this section I will go further into the topic of women as victims of HIV/AIDS and the stigma that these women face, based on theoretical perspectives of various scientific authors. The other section will present the academic debate on HIV/AIDS-related stigma, the manifestation of this kind of stigmatization in South Africa and the consequences of it. In that section I will also devote a subsection to how various scientific authors believe that the stigma can be reduced. A lot of the scientific literature I discuss in this chapter is based on research in South Africa, but there are also articles that discuss HIV/AIDS, women’s inequality and stigma in other countries or continents. Therefore, I gained a broad view on these issues based on the views of various authors and from various contexts.

3.1 HIV/AIDS AND GENDER INEQUALITY

Based on various books and articles of scientific authors, in this section I will discuss the context of HIV/AIDS in South Africa. Furthermore, I will present and discuss the debate on women’s inequality in the context of South Africa and HIV/AIDS. I think it is important to discuss the characteristics of South Africa that have influence on the HIV/AIDS epidemic and how women are positioned in society and how this is translated into the field of HIV/AIDS.

3.1.1 HIV/AIDS in South Africa

The HIV/AIDS epidemic began to spread through sub-Saharan Africa in the late 1980s. South Africa is one of the countries where the disease has hit hardest. The literature suggests a number of reasons for this. The peculiar history of South Africa has certainly contributed to the spread of HIV. The epidemic reflects the history of the country. Migration and mobility have created patterns of sexual behaviour and mixing which are perfect for the spread of sexually transmitted diseases (Barnett & Whiteside 2002: 152-153). This corresponds with Poku (2005: 76), who describes how migrants have higher infection rates than those who do not migrate, independent of the HIV prevalence at site of departure or destination. Also, according to Poku (2005: 77) the major issue of inequality in South Africa can be seen as a precedent for the spread of HIV/AIDS. Especially in South Africa, there are different forms of inequality such as racial and gender inequality. Racial inequality is often a cause of
poverty, which in turn prevents access to medical care and facilitates the spread of HIV/AIDS. But also gender inequality, for example when women have less economic opportunities and remain financially dependent or have less access to schooling, is related to the HIV/AIDS prevalence rate. Furthermore, according to Barnett and Whiteside (2002: 154), the high rates of rape in South Africa have strongly contributed to the spread of the disease. Leclerc-Madlala (2002: 87-88) argues that these high rates of rape are largely caused by gender inequality, but that there is also a myth prevailing in South Africa, the so-called ‘virgin myth’. This myth implies that sexual intercourse with a virgin is an effective treatment for HIV/AIDS. Consequently, this myth is not only a cause of the high sexual violence rates in South Africa, but it is also highly related to HIV/AIDS prevalence in the country.

Based on this literature, it can be concluded that the South African context and interrelated factors are important contributors to the HIV/AIDS prevalence in South Africa. Especially the gender inequality is an important contributor. In the next subsection, I will elaborate on the inequality of women and how this is related to HIV/AIDS by discussing the theoretical perspectives of various authors on the position of women in South Africa.

3.1.2 Women and HIV/AIDS

South Africa is a highly gender-inequitable country. Many scientific authors and researchers point out the gender-based violence and gender inequality as important determinants of women’s HIV risk (Dunkle et al. 2004: 1415). In the literature on gender inequalities in South Africa, there are a few prominent authors on this topic; Rachel Jewkes (2003; 2004; 2010), Kristin Dunkle (2004; 2010) and Robert Morrell (2010). These authors conducted several studies and wrote many articles on gender inequalities and gender based violence in relation to HIV/AIDS. In this subsection, I will first discuss their and other authors’ views on the position of women and then discuss this position with regard to HIV/AIDS.

Jewkes and Morrell (2010: 2-11) studied gender inequality related to HIV/AIDS in South Africa. Their approach criticizes various former approaches related to gender inequalities. They argue that the approaches that only focus on the genetic or physical to explain gender inequalities fail to explain diversity among men and women and fail to provide interventions that promote gender equity. Instead, Jewkes and Morrell contribute to the body of literature on gender inequality by perceiving gender differences as socially constructed. They believe in the existence of multiple constructions of masculinity. According to them, there is one masculine position that is dominant; hegemonic masculinity. This is the position that is generally associated with the oppression and subordination of women. Hegemony refers to the exercise of power by creating consent through the
establishment of accepted ideas or values. The hegemonic masculinity mobilizes and legitimates the subordination and control of women by men (Jewkes & Morrell 2010: 3). In this way, it is conceived as a necessary and integral element of a patriarchy, which is the social organization that distributes and secures power of men over women. According to Jewkes and Morrell, it is hegemonic masculinity which is particularly present in South Africa.

Jewkes and Morrell discuss the various manifestations of hegemonic masculinity (2010: 3-5). A few examples they name are the heterosexual success of men, acceptance of hierarchical authority and exercising control over women. These expressions of hegemonic masculinity in turn lead to a lot of violence against women. They state that gender inequity and gender-based violence lie in the patriarchal nature of South African society. Jewkes and Morrell (2010: 5) also argue that accepting and excusing the controlling and violent male behaviour is an integral part of femininity for African women. This corresponds with Outwater, Abrahams and Campbell who argue that violence has become normative and to a large extent accepted in South Africa (2005:139).

According to Jewkes et al., the gender power imbalance is also translated into a power imbalance in sexual interactions. Results of their study show that in South Africa, women who experience partner violence and have high gender inequity in their relationships, are at higher risk of being infected with HIV (Jewkes et al. 2010: 46). These results correspond with the results of a study by Dunkle et al., which also show that women are at greater risk of HIV infection when they experience partner violence or when they are involved with controlling male partners (2004: 1418-1420). Also Outwater, Abrahams and Campbell (2005: 150) point out that gender inequity promotes HIV infection. They state that within sexual relationships, women are supposed to give priority to their partner’s needs and wishes; sometimes this includes having unprotected sex. Jewkes et al. (2010: 41-42) further argue that women are scared to be associated with infidelity if they ask for condoms. Furthermore, according to Wojcicki (2002: 283-284), sexual violence is also common in South Africa. She argues that to some extent, there is a tolerance of rape that is linked to South African norms and values. And also, in South African society, men often have multiple partners (Jewkes, Levin & Penn-Kekana 2003: 125). Consequently, the violence, inequality in sexual relationships, high risk of being raped and the multiple sexual relationships that men have, place women at higher risk of HIV infection.

Duffy argues that women are not only more vulnerable to contracting HIV/AIDS, they are also more often and more severely stigmatized when they are HIV positive. Women are more in danger of losing belongings and their children and of endangering their own health and lives because of isolation and neglect (Duffy 2005: 16). In this paragraph I discuss some of the reasons given by various authors why women are more often and severely the victim of HIV/AIDS-related stigma than men. Wingood et al. state that women with HIV are often marginalized and encounter social hostility.
These authors think that the hostility arises from pre-existing stigmas that are gender-related, from their race, from women being perceived as the carriers of HIV or from their lower socio-economic status (Wingood et al. 2008: 239). Also according to Castro and Farmer (2005), women are more likely to experience stigma and domestic violence when they disclose their HIV positive status, they argue that this especially occurs in settings where women are unequal to men (Castro and Farmer 2005: 55). This corresponds with the article of Duffy, who argues that women are often blamed for being HIV positive. When women are HIV positive, they are often accused of being promiscuous. Women are expected to remain faithful to their husbands, whereas the infidelity or promiscuity of a man is accepted and tolerated. Even though a woman became HIV positive because she contracted the infection from her husband, the woman is often sent away or ostracized by her husband or family (Duffy 2005:16-17). Thus, according to these authors, I can state that the gender-inequality is an important cause of why women are more often and more severely the victim of HIV/AIDS-related stigma.

Based on these theoretical perspectives and research results, it can be assumed that women are more vulnerable to HIV/AIDS and the stigma than men because of gender inequality. However, the relationship between gender inequality and the stigma is not strongly emphasized by the authors I discussed. During my research, I focused more intensively on the relationship between gender inequality and the stigma. In the conclusion I will elaborate if this relationship is indeed stronger in practice than discussed in literature. In the next section, I will discuss what research carried out in the last decade on the topic of HIV/AIDS-related stigma has to say on how the stigma on women is perceived, how the stigma is manifested, what the consequences are and how the stigma can be reduced.

3.2 HIV/AIDS-RELATED STIGMA

Stigma is not a new concept, but it remains highly significant in the context of HIV/AIDS in South Africa as the stigma has a large impact on the epidemic and on the people living with HIV/AIDS in South Africa (Gilbert & Walker 2010: 139). Because of the complexity of the phenomenon and the variability in manifestations of the stigma by setting and level, there are many difficulties and disagreements on the definition of HIV/AIDS-related stigma, on how to measure stigma, how to assess the impact of stigma and on how to reduce stigma (Mahajan et al. 2008: 2). In this section, I will discuss different views on the HIV/AIDS-related stigma as perceived by various prominent scientific authors like Parker and Aggleton (2003) and Kalichman and Simbayi (2004; 2007). First of all, I will present the debate on the concept of stigma and the concept of HIV/AIDS-related stigma.
Then, I will discuss various scientific views on how the stigma is manifested and what the consequences are of the stigma on individual and societal level. Finally, I will present and discuss various perspectives on how the stigma can be reduced.

3.2.1 Stigmatization

In this subsection, I will explain the concept of HIV/AIDS-related stigma. Many of the scientific authors like Parker and Aggleton (2003), Simbayi et al. (2007) and Genberg et al. (2009) who write on the HIV/AIDS-related stigma draw on the work of Goffman (1963), who perceived stigma as a significantly discrediting attribute that serves to reduce the person who has the attribute. Someone who is stigmatized is seen as a person who possesses an undesirable attribute. What is regarded as an undesirable attribute is constituted by society. Stigma is mapped onto people, who because of their difference are negatively valued by society (Parker & Aggleton 2003: 14). This corresponds with the article of Genberg et al. (2009), in which stigmatization is defined as “a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group” (Genberg et al. 2009: 2279).

Link and Phelan (2006) provide a conceptualization of the concept of HIV/AIDS-related stigma, which highlights the various components of stigma and the relationship between these components. According to them, there are five interrelated components that act together to produce stigma; these include labelling socially relevant differences, linking the labelled individuals to undesirable characteristics, separations from those who have been labelled and experience of loss or discrimination as a result of the stigma. The last component is the exercise of power, which is very important because power is able to introduce stigmatization. Stigma removes power from the stigmatized person, increases differences and reduces the stigmatized group or person’s social status and image of self (Link & Phelan 2006: 528; see also Mahajan et al. 2008: 5; Skinner & Mfecane 2004: 157).

Stigma has been associated with incurable and severe diseases and with disease transmission that is related to individual behaviours, especially behaviours that do not conform to the social norm (Poku 2005: 74). Gilbert and Walker argue in their article that diseases associated with the highest degree of stigma share common attributes; the disease is progressive and incurable, the disease is not well-understood among the public and the symptoms cannot be concealed (Gilbert & Walker 2010: 140). All of these attributes indeed apply to HIV/AIDS. Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo (2007: 1823) argue that HIV/AIDS is probably the most stigmatized medical condition in the world. There are several reasons why there is so much stigma on HIV/AIDS. First of
all, HIV/AIDS is often seen in relation with blood, death and sex, issues that are culturally sensitive and taboo. Secondly, in earlier prevention programmes, HIV/AIDS was introduced as an ‘immoral’ disease. This probably contributed to the HIV/AIDS-related stigma that is now prevailing (Simbayi et al. 2007: 1823-24). And thirdly, according to Simbayi et al., HIV/AIDS-related stigma is inextricably entangled with other stigmas associated with risk behaviours, like sexual promiscuity, homosexuality, sexual exchange and drug use (2007: 1823-1824). Therefore, the disease has been used to stigmatize entire groups who are considered inferior. Poku (2005: 74-75) and Barnett and Whiteside (2002: 66) also argue that HIV/AIDS is perceived as an ‘immoral’ disease that particularly happens to people who do not conform to social norms. Stigma is especially relevant in relation to prevention and treatment of HIV/AIDS. According to Genberg et al. (2008: 773), HIV/AIDS-related stigma has been perceived as a barrier to HIV prevention, treatment and care. In subsection 3.2.3. I will discuss the perspectives of various authors on the consequences of HIV/AIDS-related stigma.

3.2.2 Manifestation of stigma : secrecy, discrimination and exclusion

Kalichman and Simbayi (2004), two prominent academics on the topic of HIV/AIDS, recall the results from a South African national household survey; 26 percent of the respondents would not be willing to share a meal with a person living with HIV/AIDS, 18 percent would be unwilling to sleep in the same room as someone with HIV/AIDS and 6 percent would not talk to a HIV positive person (2004: 572-573). These are some examples of how the HIV/AIDS-related stigma may be manifested. In this subsection, I will discuss more manifestations of the stigma.

When individuals find out they are HIV positive, they have the choice to either disclose their status or to keep their status a secret. Kalichman and Simbayi (2004: 573) argue that it is an expression of the stigma that a lot of people choose to keep their status to themselves. A relevant study that is conducted by Carr and Gramling (2004: 35-38) on HIV positive European-American women shows that women often have a hard time making the choice to disclose their status or not. A lot of women in their study were afraid they would be accused of promiscuity and would be rejected or ostracized if they disclosed their status. The study reported that the women argued that their greatest fear after finding out their HIV positive status was not dying, but the negative reactions of other people. This corresponds with the study of Gilbert and Walker in South Africa (2010), their respondents were also reluctant to disclose their status because of the fear to be discriminated against (Gilbert & Walker 2010: 144).

When people who are HIV positive do disclose their status, research has shown that there are indeed several visible expressions of the stigma. Skinner and Mfecane (2004: 161) describe that
one way of how the stigma is manifested is that people create distance from people who are infected with HIV/AIDS. But unfortunately, there are more and often worse ways of how stigma is expressed. Discrimination is a common manifestation of HIV/AIDS-related stigma. Many authors regard discrimination as overlapping and sometimes, erroneously, conflate it with stigmatization. According to Mahajan et al. (2008: 4-5), discrimination is defined as “when, in the absence of objective justification, a distinction is made against a person that results in that person being treated unfairly and unjustly on the basis of belonging or being perceived to belong, to a particular group”. Gilbert and Walker (2010) perceive discrimination as a response to the fears and prejudices of individuals and communities (2010: 140). Because of discrimination, people living with HIV/AIDS are systematically disadvantaged in a variety of ways including in income, medical treatment, education and health. In South Africa, discrimination has occurred frequently in relation with HIV/AIDS. Skinner and Mfecane (2004: 159-160) state that exclusion is another expression of HIV/AIDS-related stigma. People who are living with HIV/AIDS are often excluded from society in various ways. Examples of discrimination and exclusion that happened because of the prevailing HIV/AIDS-related stigma in South Africa, according to Skinner and Mfecane (2004: 159-160), are refusing HIV positive children into schools, exclusions from the work place and rejections from families and/or communities. At the most extreme, stigma may manifest itself as violence perpetrated against people living with HIV/AIDS (Wingood et al. 2008: 237). Examples of this are murders on people who revealed their HIV positive status (Skinner & Mfecane 2004: 159-160).

Secrecy, discrimination and exclusion appear to be the main expressions of the HIV/AIDS-related stigma. In the following subsection, I will discuss the consequences of the stigma, thus, the consequences of these manifestations of the stigma.

3.2.2 Consequences of stigmatization

Many scientific authors discuss the consequences of the HIV/AIDS-related stigma. These consequences occur on different levels. For example on the family level. Besides the regular problems that a family has to face during the disease of an HIV positive family member, in many local communities families affected by HIV/AIDS become subjected to stigmatization. Therefore, according to Poku (2005: 170-171) and Duffy (2005: 16) many households keep the prevalence of the disease within their family a secret and rarely or never mention the true diagnosis of the sick person.

According to Poku (2005: 150-151), the most dangerous consequences of HIV/AIDS-related stigmatization are the psycho-social and cultural constraints HIV positive people have to deal with for getting tested and receiving treatment. This is because people fear not only the disease, but also the stigma that comes with the disease. Therefore, the stigma can delay diagnosis and entrance into
treatment. Skinner and Mfecane (2004: 161) argue that people have no motivation to be tested, as the person sees no benefit when the diagnosis of HIV is regarded as equivalent to death and if they are likely to be stigmatized. This corresponds with Mahajan et al., who argue that the stigma is regarded as a barrier for getting HIV testing and treatment. And also, according to Mahajan et al., people who are aware of their HIV positive status may avoid revealing their HIV status to their partners, family and community by not participating in treatment programs. The authors emphasize that it is a downwards spiral, as the untreated HIV infection leads to the visible diseases that occur with AIDS which in turn also lead to severe stigma (Mahajan et al. 2008: 8-9). Even for people who are already aware of their HIV status, stigmatization can limit access to care and treatment. Because some HIV positive people are not able to acknowledge to their families that they are infected, they are denied that level of care by not receiving support or help from them (Skinner & Mfecane 2004: 161; Carr & Gramling 2004: 37).

Wingood et al. conducted a study on HIV positive women in South Africa and conclude that besides the obstructed access to care, the stigma also has harmful effects on the women’s mental health (2008: 239). This corresponds with Simbayi et al., who, based on a study among HIV positive men and women conclude that the stigma leads to a sense of isolation, emotional distress and depressive symptoms (2007: 1823-1830). Furthermore, studies show that stigmatization can lead to increased transmission risk behaviour, as those who experience stigma are less likely to reveal their HIV positive status to their sexual partner (Mahajan et al. 2008: 8).

Consequently, it can be stated that the harmful effects of stigma threatens to undermine the efforts to prevent and treat HIV/AIDS. Therefore, according to Visser, Makin, Vandormael, Sikkema, & Forsyt (2009: 197), implementing intervention strategies to counter the effects of stigma has become an important component in the global fight against HIV/AIDS. Most of the authors I discussed in this and in the previous subsection emphasize the secrecy as a strong manifestation of the stigma and the consequences of it. I wondered if secrecy is indeed such a strong manifestation of the stigma and if it indeed has severe consequences. In the conclusion, I will conclude if practice is consistent with the theory.

3.2.3 Interventions to reduce stigma

Parker and Aggleton (2003) argue that much of the literature on HIV/AIDS-related stigma understands stigma in highly emotional terms, for example as anger towards people living with HIV/AIDS. This literature implies that there are many people who believe that HIV positive people deserve their illness and the discrimination. Therefore, many researchers focused on the beliefs and attitudes of those who are perceived to stigmatize others. The attitudes of ‘stigmatizing’ people are
often correlated with misunderstandings and misinformation concerning HIV prevention or transmission. Misunderstandings and misinformation about HIV/AIDS are related to the emotional responses. According to Parker and Aggleton (2003: 14-16), beliefs about what is correct or incorrect become the cause of stigmatization in relation to people living or associated with HIV/AIDS. Because of this, many of the efforts to reduce stigmatization are focused on providing ‘correct’ knowledge about HIV/AIDS and on providing psychological training to deal with the emotional responses that occur when HIV/AIDS prevails in the community of people. These strategies aim to increase empathy, reduce anxiety and fear and increase contact with people infected with HIV/AIDS (Parker & Aggleton 2003: 16). Mahajan et al. also argue that the dominant stigma reducing interventions are focused on increasing tolerance of people living with HIV/AIDS by means of the provision of factual information about HIV/AIDS (Mahajan et al. 2008: 9-10). According to Kalichman en Simbayi (2004: 578), particularly providing factual information on HIV/AIDS for people who hold traditional beliefs about the cause of HIV/AIDS can prove useful in reducing the stigma.

However, there is also criticism on these stigma reducing efforts. These efforts such as information based awareness programs are designed to reduce ignorance about people living with HIV/AIDS. But according to Campbell, Foulis, Maimane and Sibiya (2005: 808), even though ignorance often plays a key role in stimulating stigma, to provide people with factual information about the contagiousness of HIV/AIDS does not seem to lead to widespread stigma reduction. Furthermore, Parker and Aggleton (2003) argue that the focus should not be on individual behaviour, because stigmatization is a social and cultural phenomenon linked to the actions of entire groups of people. This corresponds with Barnett and Whiteside (2002: 66) who argue that stigmatization is a social process that reflects the tensions in social relations and conflicts that prevail in every society and culture. Genberg et al. (2008: 773) also argue that efforts to reduce stigma have been focused on the individual level rather than that these efforts addressed the root causes of stigmatizing attitudes. Instead, Genberg et al. emphasize that measures are needed that focus on the attitudes of community members regarding HIV/AIDS.

Another strategy for reducing stigma that is mentioned by Campbell et al. (2005: 808) is making discrimination against people living with HIV/AIDS a punishable offense. Laws on antidiscrimination have the potential to reduce explicit and public stigmatization of HIV positive people (Campbell et al. 2005: 808). Laws also need to be implemented though and therefore, Simbayi et al. (2007) conclude that anti-discrimination laws need enforcement (2007: 1830). The problem with that is that manifestations of stigma are often not very obvious and are rooted within individual psyches, families, communities and are beyond the reach of a legal system. Based on these limitations, Campbell et al. argue that the anti-discrimination laws may be a necessary measure to fight stigmatization, but are certainly not sufficient (2005: 808).
Another HIV/AIDS-related stigma reducing strategy is television. A good example of how this might work is presented by Mahajan et al. (2008), who describe how a broadcast in Botswana, where viewers were exposed to a two-year HIV story line in The Bold and the Beautiful soap opera. This indeed has led to significantly lower levels of HIV/AIDS-related stigma (Mahajan et al. 2008: 9-10).

Campbell et al. argue that according to them, the best strategy for reducing stigmatization is to involve community members in anti-stigma efforts. This should be combined with education and legislation. They argue that the key to success is to promote initiatives for debate and dialogue within a group of people, especially in marginalized communities where social obstacles may undermine attitudes or behaviour change. Through such dialogue, a group can develop critical understandings of such damaging behaviours or attitudes and enhance their awareness of the obstacles they have to face and the collective action that is needed to challenge the obstacles. Communities need to be mobilized to engage in critical thinking about the things that feed the stigmatization of people living with HIV/AIDS. Initiatives to tackle the social root causes of stigma are certainly needed according to Campbell et al. (2005: 808-814).

Based on this theoretical discussion, it can be stated that there is not much agreement on which intervention can serve to reduce the stigma. I do not think that there is a clear-cut answer on which method is most effective. Rather, I think that a method to reduce stigma should include different elements to prove effective on multiple levels, thus, for example, not only by providing factual information, but also by reducing the prejudices on HIV positive women. During my research I focused on how the stigma can be reduced based on the various perspectives of my participants. Therefore, based on their professional expertise and knowledge, I hoped to gain methods that include various elements that will serve to reduce the stigma on multiple levels.

This theoretical framework provided me with important insights that have laid the foundation for conducting my research. First of all, I discussed authors on HIV/AIDS; how HIV/AIDS is placed in the context of South Africa and the impact it has on women. This was very important contextual information for conducting my research, as the HIV/AIDS prevalence in my research location is extremely high. Also, women are the topic of my research, and these theoretical insights provided me with perspectives on how they suffer from HIV/AIDS and the stigma. Furthermore, the literature on stigmatization provided me with theoretical insights on how stigma is perceived, on how it is visible and how it manifests itself and on what consequences stigmatization can have. These insights were important to take into account when I investigated these same topics based on the perspectives of the actors involved with Bobbi Bear. Finally, the articles that discussed interventions to reduce stigma were very useful, as I investigated how my research participants think the stigma can be reduced.
4. RESEARCH METHODOLOGY AND METHODS

On the 17th of July, I went to South Africa to start my fieldwork. I stayed in Amanzimtoti, a town in the province of KwaZulu-Natal and I conducted my research at Bobbi Bear. Bobbi Bear had an important role during my research; Bobbi Bear staff members participated in my research and some of the Bobbi Bear staff members helped me to find people willing to participate in my research. I stayed at Bobbi Bear for almost ten weeks, and in those ten weeks I conducted my research. In this chapter, I will present the methodology of this research and the different methods I used for conducting my research. Also, I will elaborate on how I experienced the process of doing research and how I dealt with the difficulties I encountered during my research.

4.1 METHODOLOGY

Ontology is occupied with what reality is. It is a theory concerning what ‘exists’ and what is ‘knowable’ (Summer & Tribe 2008: 55). In this research, I adopted an ontological position described as constructionist. Constructionist implies that the social properties are “outcomes of the interactions between individuals, rather than phenomena separate from those involved in its construction” (Bryman 2008: 366). The HIV/AIDS-related stigma that I investigated during my research is an example of an outcome of interaction between individuals. Without the influence of these interactions, there would be no stigma. Thus, stigma is not separated from the people involved in its construction. Epistemology is concerned with the nature of knowledge itself. It is important to be aware of the epistemology of a research, as it informs the choice of the theoretical and/or conceptual framework that in turn influences the methodology and methods (Summer & Tribe 2008: 55). The epistemological position that I adopted during my research has been an interpretivist position. An interpretivist position implies that the researcher focuses on the understanding of the social world through an investigation of the interpretation of that world by the participants (Bryman 2008: 366). During my research, I investigated the interpretation of the social world of my participants, by discovering how my participants perceive the HIV/AIDS-related stigma in their communities and how they think it can be reduced.

4.2 UNIT OF ANALYSIS

Before going to the field, I already knew that the topic I chose to investigate was sensitive and difficult to discuss. HIV/AIDS is a sensitive topic to discuss, especially in South Africa, a country with a
specific past that suffers enormously from the effects of HIV/AIDS. There is a lot of stigma on the disease, which makes it difficult to investigate anything related to it. Therefore, I had to think carefully of a strategy that would help me gain the information that I needed to answer my research, but that would also not cross any boundaries of the people I wanted to include in my research. At first, I wanted to focus on staff members of Bobbi Bear and women living in the local community where Bobbi Bear operates. As reaching out to the women did not work out as I intended (I will elaborate on this in the reflection section), I eventually focused my research on Bobbi Bear’s staff members and other professional actors that are in some way or other involved with Bobbi Bear. These other actors were external psychologists and counsellors who work with Bobbi Bear, managers of HIV/AIDS clinics, directors and staff members of other NGOs that cooperate with Bobbi Bear and a police officer that also cooperates with Bobbi Bear. Furthermore, I got the chance to interview a former activist who now is chair member of a political party and member of the South African parliament. That person is related to the director of Bobbi Bear, therefore I was able to arrange an interview with her. All of these participants had experience with women who have to face the stigma. Because these people are from different backgrounds and have different types of expertise, I reckoned that I would gain an extensive and varied view on the HIV/AIDS-related stigma and on how they think the stigma can be reduced. I also conducted interviews with high school students who did a school project at Bobbi Bear and four college students, who cooperated with another NGO that also works with Bobbi Bear. These participants were not professional actors and therefore I only used the results of these interviews as background information about HIV/AIDS and the stigma.

My research participants all live and work in the communities surrounding Bobbi Bear. These communities vary from black and white, poor and rich and urban and rural communities. I wanted to find out how my research participants perceive the stigma on HIV/AIDS in the community where they live and work. Almost all of my research participants work with women who are HIV positive and have to face stigma. Therefore, I gained a perspective of how my research participants see and experience the stigma, but also, more indirectly, how HIV positive women experience the stigma. So even though I did not directly talk to HIV positive women who face the stigma, or maybe I did but I never asked the status of my research participants, I gained a proximate view of how HIV positive women in the communities surrounding Bobbi Bear experience the stigma. Also, the questions I asked my research participants on how they think the stigma can be reduced, are based on their own perceptions of the stigma, but also on their experiences with stigmatized HIV positive women. Consequently, the answer on the second part of my research question on how stigma can be reduced indirectly includes the view of stigmatized HIV positive women.

I selected my participants based on purposive sampling. This type of sampling implies that I selected my participants with a purpose in mind, with the research questions as a reference for
selection (Bryman 2008: 375). Purposive sampling covers a wide range of approaches, an example of this is snowball sampling. I also made use of snowballing, which means that I asked my participants if they could recommend other participants (Small 2009: 14). I looked for participants who are involved with Bobbi Bear and have to deal with HIV positive women in their daily work. All of my research participants are in some way involved with Bobbi Bear and all of them have to deal with HIV positive women in their work. I do not know if one of my participants was HIV positive, but all of my participants were HIV affected, meaning that a friend or someone in their family is or was HIV positive.

4.3 RESEARCH METHODS

To obtain data for answering my research question, I used different methods. This is called triangulation, which implies an effort to obtain convergence and validation of the results by means of different methods studying the same phenomenon (Johnson & Onwuegbuzie 2004: 22). The research that I conducted at Bobbi Bear has been qualitative of nature. I used qualitative methods because I wanted to produce and document a rich set of accounts based on my participant’s experiences, knowledge, ideas and impressions (Alvesson 2009: 156-157). Therefore I chose to conduct a research that is qualitative of nature, because that would provide me with the most in-depth information about how the actors that are involved with Bobbi Bear perceive stigmatization. The other method I used for my research were participatory methods, in particular focus group interviews. I considered quantitative research, but because of the sensitivity of my research topic, it did not seem appropriate to use quantitative methods. Furthermore, the information I wanted to achieve required in-depth information about my participants’ views on and experiences with HIV/AIDS-related stigma. During my research, I used the methods of in-depth semi-structured interviews, informal conversations, observations and focus groups. I will address these different methods more extensively below.

The type of interview that has been most convenient for my research were semi-structured interviews. This type of interview provided me with a guideline for questions that I wanted to ask, but these questions did not need to be slavishly followed (Neyland 2008: 112-113). I used this type of interviewing because I knew which questions I wanted to be answered and because I knew in which direction the interview had to go. However, I left room to ask questions that could derive from the answers of my participants. A semi-structured interview may provide much in-depth data on issues that are unexpectedly relevant for understanding the setting (Neyland 2008: 113). This type of interviewing showed my participants that I am prepared, but that there is room for the participant to follow a new lead (Russell 2002: 210). That happened a lot during my interviews, my participants
often mentioned unexpected but interesting things that I wanted to elaborate on. Because I used a semi-structured interview, I was provided with the possibility to go deeper into what my participant mentioned. The main challenges I faced during the semi-structured interviews were keeping the interview focused. Some of my participants often deviated from the topic, and then it was hard to distinguish what was relevant for my interview or not. I tried to steer the interview so that it would not deviate from the topic. Also, I tried to obtain as much relevant information as possible by asking probing questions, follow-up questions and specifying questions (Bryman 2008: 444-445). Most of the time, I conducted one-on-one interviews, but I also had in-depth interviews with two, three or four persons.

Focus group interview is another technique I used to obtain data. I wanted to engage people who are involved with Bobbi Bear in a discussion on the stigma (Hunt & Spreckley 2005: 147-148). The main aim of a focus group is to understand the meanings, beliefs and cultures that influence the feelings, attitudes and behaviours of individuals. The added value this method had for my research is that the group dynamics are highlighted and therefore the data generated through the social interaction of the group was often deeper and richer than the one-to-one interviews. Furthermore, the focus group interviews provided me with information about the range of ideas and feelings of my participants about the issues of HIV/AIDS and stigmatization. Also, the interviews illuminated the difference in perspectives between individuals (Rabiee 2004: 655-656). I chose the research participants in the focus groups based on similar characteristics. The focus group interviews were composed of Bobbi Bear women coming from both black and white communities and of male and female students also coming from both black and white communities. In that way, I got an opportunity to understand their knowledge, attitudes and feelings towards HIV/AIDS and the stigma that comes with it (Hunt & Spreckley 2005: 147-148). These feelings and perspectives were influenced by the cultures of and the experiences in the communities my participants live in. The focus groups highlighted the dynamics but also the similarities of the stigma on HIV/AIDS between the black and white participants.

I also used participant observation as a method to obtain data for my research. Participant observation requires a close attention to detail at events and interactions. The researcher has to immerse oneself in the social context that is being studied and the researcher has to be open to the events and interactions that take place (Van Der Waal 2009: 34-35). I did not intend to use participant observation as an important method to gain data, but because I worked with Bobbi Bear staff members every day, I could observe the people I was participating with. I recorded my experiences in a field journal. This journal reflected the observations about the people I interacted with as well as some of my sentiments about participating in the group (Steinberg 2006: 90-91). These observations helped me to gain an understanding of how my research participants talk about
HIV/AIDS and the stigma with their colleagues and with the people who visited the Bobbi Bear centre. I also observed how they deal with HIV positive clients that they have to bring to AIDS clinics. And finally, the difficulties I encountered with finding interview participants were also an important observation for my research, as these observations indicated the presence of the stigma. I will elaborate on these difficulties in the reflection section.

The final methods I used for my research were informal conversations and informal group discussions. These conversations and discussions proved to be a very useful source of information. This had to do with the sensitivity of my research topic. In the beginning of my research, I experienced some difficulties in arranging in-depth interviews with Bobbi Bear staff members. A lot of them did not want to be interviewed and especially not about HIV/AIDS. I will elaborate on these difficulties in my reflection section. When I explained my research to these staff members, although they did not want to be interviewed, the things they did say about HIV/AIDS were also valuable for my research. Furthermore, I had a lot of informal conversations with other actors involved with Bobbi Bear and staff members who were willing to talk about HIV/AIDS and the stigma. And sometimes informal group discussions spontaneously arose between staff members at Bobbi Bear or other people involved with Bobbi Bear that I met during my research (Hunt & Spreckley 2005: 150). Because in the first weeks I did not conduct any formal in-depth interview but only observed, explained my research and talked to the people working or involved at Bobbi Bear, I gained a lot of information by means of informal conversations or spontaneous group discussions.

To assure a high quality research, I used the following criteria to assess my research. First of all, I assessed my research on trustworthiness. I tried to achieve trustworthiness by triangulation, producing a rich account of the details and by consolidating what has been said in one interview by means of asking it in another interview. For example, if one interview participant said that rape revenge happens a lot, I checked with another participant if he or she also argues that revenge rape happens a lot. Authenticity is another criteria that I used to assure the quality of my research. I tried to achieve this by fairly representing my participants’ views. Furthermore, transparency about the used methods and a reflexive stance are important to assure a good quality of my research (Bryman 2008: 377-380), this transparency and reflexive stance can be seen in my reflection section.

4.4 THE FIELDWORK

4.4.1 In the field

When I arrived at Bobbi Bear, I had a clear view of how I wanted to conduct my research. The first two weeks I wanted to get to know Bobbi Bear and its staff members. After that, I wanted to start
interviewing the Bobbi Bear staff members and women in the local community where Bobbi Bear operates. However, my plan did not entirely work out as I intended. During my research, it became clear that as a researcher I had to be flexible and adapt myself to the circumstances. Throughout my stay at Bobbi Bear, there were a lot of crisis situations going on involving children. That is the work of Bobbi Bear, but I felt that my help was needed so I did the best I could to assist the Bobbi Bear members with their work. Therefore, I was often busy at Bobbi Bear, especially the first weeks. On the one hand, that made it difficult to look for research participants who were willing to conduct an interview with me. On the other hand, it also gave me a chance to observe and have informal conversations with Bobbi Bear staff members. Also, I got to know the organization Bobbi Bear and its staff members very well and I had a chance to do something for this organization. After a few weeks, I finally had a chance to conduct my interviews. I had to change my research question a bit, for reasons I will explain in the next section, because that would make it easier for me to conduct interviews and to gain information about HIV/AIDS-related stigma in the communities of my participants. The first three weeks were only based on observation and informal conversations. The other seven weeks, I conducted 15 on-on-one in-depth semi-structured interviews with people involved with Bobbi Bear, four group interviews and three focus groups. I continued working for Bobbi Bear for the whole period, but because I stayed at Bobbi Bear and most of my interviews took place at the Bobbi Bear centre, that did not interfere with my research objectives. At the end of my stay, I reached the stage where I started to notice that I did not collect new information anymore and that I kept getting the same answers to my questions. This is called informational sufficiency (Neyland 2008) or saturation (Small 2009: 25). Informational sufficiency is the stage in which the researcher comes to understand that their data is sufficient for writing a research report (Neyland 2008: 148-149). Thus, at the end of my stay, I fortunately had the feeling that I collected enough data to write my thesis.

4.4.2 Data processing

I recorded all of my interviews and focus groups with a tape recorder. After every interview, focus group, informal conversation about my research or my research topic and after every relevant observation, I took notes in my field journal. Eventually, I built up a record of the flows of events witnessed and the people I talked to during my entire research period (Van der Waal 2009: 34-35). That was one of the things that I found very important in my research; to write down everything. My argument for writing down all of my observations, experiences and conversations was that I would be able to produce a richly written account. Besides taking notes during observations, conversations and interviews, I wrote a reflection of every day I spent at Bobbi Bear. This was something I did very
consistently. It would provide me with a written account of everything I did, observed, thought, experienced and wondered about during my stay at Bobbi Bear. It would give me the opportunity to reflect on my thoughts and on what I did and observed during my fieldwork. And more pragmatically; by writing it all down I would not leave out any important information when writing my thesis.

In the end, the data analysis of my interview transcriptions, field notes and reflections helped me to get a coherent overview of the things I saw, people I encountered and conversations and interviews that were held. It provided me with a rich file of data that led to the formation of my thesis.

4.5 REFLECTION

A researcher is part of the social world he is studying and subject to distinctive purposes, limitations and weaknesses. This influences the control you have on your research (Hammersley & Atkinson 1995: 286-287). The limitations, weaknesses and purposes can influence or even alter a research. In this section, I will describe the limitations of my research and problems I encountered while doing research. I will elaborate on how I dealt with these limitations and problems.

4.5.1 Ethical issues

When conducting a research, there are some ethical issues a researcher has to take into consideration. The most important thing is that the research does not have negative implications for the research participants (Scheyvens, Nowak & Scheyvens 2003: 140-141). In my case, I had to take into account the sensitivity of the topic that I investigated. After carefully constructing my interview guide, I discussed my questions with different people working at Bobbi Bear. I wanted to know if my questions were appropriate, if I used the correct way of naming some terms and how they think I should approach the issue of HIV/AIDS. To be conscious of these issues and to approach them appropriately, I also had to take into account the Zulu culture. I had to be aware of the fact that HIV/AIDS, sexual intercourse, body parts and even blood are sensitive topics which I had to address carefully. I achieved this with help from Bobbi Bear staff members.

Furthermore, I had to take into account my position as a researcher and the effects that my research might have on my participants. I solved this problem by asking about their opinion and perspective on HIV/AIDS-related stigma and not asking about personal experiences. However, some of my research participants did not have a problem talking about their own experiences with HIV/AIDS and they told me a lot of personal stories that involved HIV/AIDS and the stigma. Also, to be reliable and to emphasize the confidentiality of the conversations, I assured all of my participants
their anonymity in the research. I guaranteed that their identity would be kept private and that they would not be personally identifiable in the outputs of my research (Scheyvens, Nowak & Scheyvens 2003: 146).

4.5.2 Problems

I already was aware of the sensitivity of my research topic before I arrived at Bobbi Bear. I tried to solve this by constructing an interview guide that did not involve personal questions about HIV/AIDS and the stigma. Also, I first discussed my interview guide with the director of Bobbi Bear. She agreed with my interview guide, she thought my questions were appropriate to ask and not sensitive because I asked about my participant’s view and opinion on HIV/AIDS-related stigma and not about personal experiences with HIV/AIDS and stigma. My first intention was to interview staff members working at Bobbi Bear and women in the local community where Bobbi Bear operates. That community would be the Ilovo community, and I intended to conduct interviews with women who visited Bobbi Bear’s weekly project called Tree Clinic. Tree Clinic is a support group for women living in the rural community of Ilovo. Every Friday, women gather under a large Tree to receive support, counselling, food and clothes. It would be too dangerous for me to go to their houses and conduct interviews and too much of a hassle to transport the women to the Bobbi Bear centre for the interviews so therefore I wanted to conduct my interviews under a Tree every Friday. The first problem I encountered when I wanted to interview those women was that the director of Bobbi Bear was not available on the first Fridays. So I had to arrange interviews with the help of other Bobbi Bear staff members. But they were unwilling to help me find women who would want to have an interview with me. They argued that the topic was too sensitive and that they did not want to bother those women with interviews. I was not allowed to arrange interviews myself. So I had to wait until the director, who maintained close relationships with those women coming to the Tree Clinic, was available to help me arrange interviews. Unfortunately, on the few Fridays that she was available, it was raining so hard that the Tree Clinic was cancelled. Consequently, I had to make another plan. I decided to focus on the different actors that were involved with Bobbi Bear, because I noticed that there were a lot of people involved with Bobbi Bear from different professions. In the end, it was probably better that I did not interview the women from the Ilovo community, because these women were coming to the Tree Clinics for years. That meant that the women received a lot of counselling and education on HIV/AIDS already. Therefore, the women in the Ilovo community were probably more educated about HIV/AIDS and would have different views on stigma than women from another rural community.

Not only was it difficult to get interviews with the women from the Ilovo community; also
some of the Bobbi Bear staff members were unwilling to have an interview with me. Even though I showed them my interview guides, explained them that I did not want to ask them any personal questions but only wanted their professional perception on stigma and guaranteed them anonymity, they did not want to have an interview with me. This had not only to do with the sensitivity of the topic, but also with the fact that previous researchers had betrayed their trust by distributing personal information about their lives and their HIV status on the internet. Therefore, some of the staff members were suspicious towards researchers. I tried to prove myself trustworthy and some of the staff members changed their minds and participated as my interview participant or in a focus group, whether under pressure of Bobbi Bear’s director or not, but some of them remained unwilling. However, I did have some valuable informal conversations with them and fortunately, I found enough other research participants who did want to have an interview with me or participate in my focus group. And in the end, I obtained sufficient and relevant information about HIV/AIDS-related stigma based on different perspectives.

Finally, a problem that I encountered and that I already was expecting beforehand was that I probably would not conduct interviews with women who have to face the stigma themselves. That presumption became reality, as the sensitivity of HIV/AIDS and stigma was even worse than I expected. I could not ask any personal questions regarding HIV/AIDS and stigma, let alone ask women about their own status and how they are stigmatized. I avoided the pitfall of not knowing how HIV positive women themselves are stigmatized by means of interviewing people who have a lot of experience with HIV positive women in their daily work and life. As said before, I interviewed, for example, several psychologists and counsellors who have HIV positive women coming in for testing and counselling during their disease. Therefore, I obtained (second-hand) information about how women in the communities where Bobbi Bear operates experience and perceive the stigma. In this chapter, I discussed the methods I used during my research and the problems I encountered and how I dealt with these problems. In the next chapter, I will present the results of my research.
5. DATA ANALYSIS

HIV/AIDS is a major problem in South Africa. The prevalence rates are high and even though a lot of money has been spent on HIV/AIDS education, the prevalence rates do not decrease. Mortality rates are also high, even though a large proportion of South Africa’s population has access to ARVs (Republic of South Africa 2010). In this chapter, I will present my findings that provide insight into how my research participants view the HIV/AIDS-related stigma on women and what they think are appropriate methods that will help to reduce this stigma.

This chapter is divided into four sections. The first section will deal with how my research participants perceive the stigma in the communities where Bobbi Bear operates and what they think is the cause of the stigma. In the second section I will present why women are often the victim of HIV/AIDS-related stigmatization. The third section is based on how the stigma is manifested according to my participants and I will explain the consequences of the stigma in the communities where Bobbi Bear operates. And finally, I will present possible interventions to reduce the stigma on HIV, based on the ideas and perceptions of my research participants.

5.1 HOW IS THE STIGMA PERCEIVED?

In this section I will explain how the stigma is perceived according to my research participants. This is based on their experiences they have with stigma or people who have to face the stigma.

5.1.1 Stigma in South Africa

In South Africa, there is a very high HIV prevalence rate. Based on my participants views, this can be contributed to the fact that men often have multiple partners and to the urban migration. In the communities where Bobbi Bear operates, a large percentage of the women are infected with HIV. This is supported by a study from 2007 that shows that the prevalence rate of women between 25 and 29 years old in KwaZulu-Natal is more than 50 percent (Welz & Hosegood et al. 2007: 1469). And according to the statistics of an AIDS clinic that Bobbi Bear works with, there are more women than men coming forward to be tested and who are tested positive. Therefore it can be assumed that HIV is highly present in the daily lives of women in KwaZulu-Natal. However, the HIV status of a person is a very sensitive topic to discuss. People do not like to talk about HIV, as I experienced myself when I encountered difficulties with finding research participants. The sensitivity of the topic is also expressed by the fact that Bobbi Bear staff members often explained how important it is to never ask a person about his status, but instead ask if that person knows his status. Even though HIV exists for quite a while, it is still not a conversation topic. When I asked one of the staff members at Bobbi Bear
why, he answered that people cannot talk about it because of the stigma. Especially when someone is HIV positive, it is very difficult for that person to disclose his/her status in the community. Because of the stigma, because of the potential consequences that derive from the stigma. My participants often described the HIV/AIDS-related stigma as the label that is put on a HIV positive person. 

“it is the alienation of an individual, the ostracizing of that individual with no proof really of what that stigma is, labelling someone with something unfounded.” (counsellor Bobbi Bear)

“If you have HIV, people would not see you as an individual but as someone who is HIV positive, that person has got AIDS and whenever people refer to her they would not forget referring to that she is also HIV positive so that is like a stigma. Something that someone would carry for the rest of their lives.” (external counsellor)

“They stereotype people with HIV; you should stay away from those people, they are contaminated.” (external counsellor)

According to my participants and to what I observed, the stigma on HIV is very high in South Africa. But the stigma is not as bad as it used to be, when women were killed for being HIV positive.

“Ten years ago it used to be so much worse. If you were to come out in your community it doesn’t matter what the community was, black or white, you would be send out of the community. In white communities people would sort of ignore you, maybe freeze you out. And in black communities it would even be so bad that people would beat you to death.” (employee other NGO)

During my research, I was often referred to the story of Gugu Dlamini, the woman who disclosed her HIV positive status on radio and was later on beaten to death by her community. My participants also told me stories about women who were thrown out of the community because of their HIV positive status. And one woman who worked with Bobbi Bear told me about a HIV positive woman whom she knew very well, who was also beaten to death when her community found out about her status. My participants argued that the stigma is not that bad anymore, because more people become aware of their own status and of the fact that so many people in their communities are HIV positive. Also, more people are educated about HIV/AIDS. Therefore, people are more tolerant towards HIV positive people who disclose their status.

“But there is still a big stigma, people often keep their status a secret.” (police officer)

My participants pointed out the changes that took place; they argued that now it is much easier for women to speak about HIV and even go to clinics and fetch ARVs, whether the medicine are for themselves or for a relative. This was not possible a few years ago. Also, HIV positive people
who disclosed their status are not excluded from churches anymore. Another example of how the stigma has become less is the story of the manager of an HIV/AIDS clinic who told me that they recently had three female speakers telling their stories of living with HIV to the women at the clinic. The manager argued that there are now more women who speak freely about being HIV positive.

The stigma also depends on the counselling a person has had. In this thesis, when I refer to counselling, I refer to both pre- and post-test counselling and counselling during the course of the disease. A large part of my interview participants are qualified pre-and post-test counsellors and often give counselling to HIV positive women. They argued that pre-and post-test counselling is an obligatory part of testing for HIV, but in some cases not done properly or not done at all. With pre- and post-test counselling, according to my research participants, a person that gets tested receives information about the test and the disease and if tested positive, information about how to deal with the disease and how to live a healthy life with medication. After the pre-and post-test counselling, there are other forms of counselling. My research participants who are counsellors often mentioned that they organized counselling sessions for groups of women who were just tested HIV positive, or that they had one-on-one sessions with HIV positive women or with HIV positive women and their family members. In those counselling sessions, the disease is discussed, or the proper use of medication, or how to live a positive life with HIV. According to my participants, counselling can lead to HIV positive women and even their family members having more knowledge and awareness about the disease. Counselling can reduce and even get rid of the prevailing prejudices on HIV. In the final section of this chapter, I will elaborate on this and other methods that can help to reduce the stigma.

The stigma mainly entails that people are treated differently because they are HIV positive. Many participants argued that people who did not have proper education about the disease, often are afraid to get near people who are HIV positive, because they are scared to become HIV positive themselves. A lot of people think you can become HIV positive by eating from the same plates or cutlery or using the same toilets as someone who has got HIV. But not only are people scared to become infected themselves, HIV positive people are also often treated differently because they are labelled as promiscuous people, who have been sleeping around. This is especially the case with women, I will elaborate upon this in upcoming sections.

“Others think for you. They think you got HIV by sleeping around so they start to call you names they think you are irresponsible, a person who does not care for herself. Especially if you are a woman. They will hurt you if you are HIV positive because they think you got it from sleeping around.” (college student)

Two of my participants, each individually told me a story about a woman living with cancer and a woman living with HIV. The woman with cancer received a lot of support from her community, but
the HIV positive woman did not receive any support when she became very ill. This points out the difference; there is no stigma on cancer, but there is stigma on HIV. If someone is HIV positive, other people do not want to come near that person because they are afraid to get the disease as well. And also, when someone is HIV positive, people think it is his or her own fault because in their view, that person has been promiscuous. Whereas with cancer, a person is completely ‘innocent’.

Because of the stigma, I could not find women who have to face the stigma themselves. However, I did find out how my female research participants would deal with the stigma. I performed a focus group consisting of staff members at Bobbi Bear in where I asked them what they would do if they were tested HIV positive and who they would tell. They answered that they would be scared and would only tell people they would trust completely, if not keep it a secret.

Figure 4: Outcomes of focus group

This surprised me, because all of these staff members are educated on HIV/AIDS and empowered. They work with rape victims, who are very often HIV positive. Therefore, their occupational risk of becoming HIV positive is high, but the women would still not disclose their status. This clearly indicates the presence of the stigma; these educated and empowered women would not disclose their status because of how their communities would react on them being HIV positive. Probably, their answers were based on experiences of their clients, colleagues or relatives and therefore they knew what the consequences of disclosing their status would be.
“You can tell everyone you are fat, you can tell everyone you have high blood pressure, you got sugar problems. But you cannot tell you are HIV positive, that will never change.” (police officer)

All of my research participants argued that when a woman discloses her status, she is often treated differently by her community or even by her family. A woman who is HIV positive is often regarded as inferior. People would think the woman has been promiscuous and now she is not able to give birth to an HIV negative child.

“They think you’ve been sleeping around, you are the wrong one. Without even knowing the story.” (external counsellor)

According to my participants, the role of a woman in the community also changes when she discloses her status. One of my participants told me a story about a woman in his community who worked as a youth leader and revealed her HIV positive status. She was dismissed from her position. The arguments were that now she is not a person anymore that children are supposed to look up to. How can children learn from someone who has been promiscuous? Often, when a woman is HIV positive and the community members know, she is regarded as a ‘wrong’ person. Even the family of a HIV positive woman is sometimes treated differently by the community. Based on the stories of some of my participants, it appears that children of a HIV positive woman are sometimes targeted at school or in the community. They are often bullied because their mother ‘has been promiscuous’ or they are avoided because other people are afraid the children are infected as well. My participants argued that this is the same for other family members, they are often avoided in the community because people are scared they are HIV positive too. Family therefore often decides to keep the HIV positive status of their family member a secret. According to my participants, if a woman falls ill, the family will say she has another disease, like pneumonia or TB. This corresponds with my observations, when I talked to people who lost a relative, they would say that person was ‘sick’. They would not tell that that person died because of AIDS. My participants argued that in some cases, the family of a HIV positive woman even decides that they do not want anything to do with her and chase her away, because she has brought shame on the family. And because a woman is scared she will be treated differently by her community and family, or even that she will be abandoned by her family or partner, my participants argued that the woman will often hide her status from them. Obviously, the chances of being stigmatized also correspond with the visibility of the disease. Many of the HIV counsellors I interviewed argued that when a woman who has not disclosed her status loses a lot of weight or when opportunistic infections like skin infections become visible, people start to gossip about her status and start stigmatizing her.
Based on the outcomes in this subsection, I can argue that the stigma on HIV positive women in the surrounding communities of Bobbi Bear is quite high. The stigma is not as bad as it used to be, when women were killed for being HIV positive, but still, women who are HIV positive and disclose their status are often treated differently by their communities or even by their families. Therefore, a woman who is HIV positive, often decides to keep her status a secret. People do not talk about HIV/AIDS, it is a topic that people want to avoid in conversations. This is in accordance with my own observations, as I experienced difficulties finding people willing to talk about HIV/AIDS. The topic is too sensitive. The interview results are highly corresponding, probably this has to do with the fact that the participants I interviewed all have to deal with HIV positive women in their daily work and therefore know how women are treated by their family and community.

5.1.2 Stigma on women

During my research, I focused on the HIV/AIDS-related stigma on women. According to my research participants, HIV positive women suffer more consequences of the stigma than men. For example, a HIV positive woman is less likely to get married and married HIV positive women are often abandoned by their husbands. This is because the people around her will think the woman has been sleeping around and no man wants to be with a promiscuous woman.

“The minute they divulge their status, they become like pariahs. There is more acceptance now than there used to be. But it is often that the men will leave the women.” (politician)

My participants argued that even though a woman got infected with HIV by blood or by her unfaithful husband, people in her community would assume that she got it by being promiscuous.

“They don’t think of that you might have been infected either through rape or that you might have been infected by an unfaithful partner, it’s not that you have been promiscuous. But that’s the impression people get on a woman when she reveals her status ‘oh she has been promiscuous’. “ (manager HIV/AIDS clinic)

People are less judgemental on men, as men are ‘allowed’ to be promiscuous and when a man is HIV positive, it is seen as the woman’s fault.

“Because of the patriarchal society, men will think it is the woman who gave me AIDS. They don’t think because I slept with ten people I might be the one who spread it.” (politician)
In the next section, I will explain more about why women are unequal compared to men and why women are often blamed for HIV.

My participants often told me stories about women who were thrown out by their communities or beaten because they were HIV positive. This happened particularly in rural communities. But apparently, this also happened in white communities. When I asked the white women who worked at Bobbi Bear if they would tell their partners if they got tested HIV positive, they answered no. They would not tell their community because they are afraid to be excluded and they would not inform their partner because they think their partner would assume that she slept around.

“Getting it from child’s blood or something, he wouldn’t think of that.” (director Bobbi Bear)

One of the women at Bobbi Bear told me a story about a baby who was in her care for a few months. At one moment, the woman and the baby both got a wound and the baby’s blood came straight into the blood of the woman. She got the baby tested and the results were positive. She went on PEP (Post Exposure Prophylaxis) but was terrified to tell her husband. She had a HIV counsellor at Bobbi Bear to tell her husband and explained what happened. The woman argued that she was scared that without help from that counsellor, her husband would not believe she did not have an affair with another man. The woman who told me this story is white and married to a white man. In the next section I will present more information about the stigma in the white communities.

5.1.3 “Black and white; we are all the same”

One of the results that struck me the most during my research was that the stigma on HIV is also highly present in the white communities. During informal conversations, interviews and focus-groups, I discovered that there is a lot of stigma going on in the white communities. Based on some of the stories I heard, it appears that the stigma on HIV/AIDS is at least as bad as in the black communities where Bobbi Bear operates. I did not expect that, I associated stigma with a lack of knowledge about the disease and I assumed that the white communities, who have enough access to knowledge, would be well-informed about HIV/AIDS. However, it appeared that there is a huge lack of knowledge in the white communities on HIV/AIDS, even though there is access to knowledge.

In the white communities, where a lot of my research participants come from, HIV is not talked about. The people in their communities do not talk about HIV, it is a topic they do not want to discuss or have anything to do with.
“HIV/AIDS is a no-go topic, no one wants to talk about it. Because the white churches are not talking about it and most of the people go with what they hear in churches. But you don’t hear about HIV in churches because the churches think it is a sin disease.” (police officer)

My research participants from white communities argued that the problem in the white communities is that most of the people think HIV is only for black people. Therefore, people in the white communities are often uneducated about HIV and AIDS. According to these participants, people in the white communities do not listen or pay attention to information about HIV, because they think it does not concern them. They think it only happens in black communities.

“I think they are a lot more naïve in terms that they think it won’t happen to them. A lot of white people don’t think they will get HIV, it is not real to them.” (employee other NGO)

One of my white participants mentioned the example of her going to the hospital for a blood test. As she noticed that the nurse who took the blood test was not wearing gloves, my participant asked the nurse why she did not wear gloves. The nurse answered that my participant looked innocent. Because she was a young white woman, the nurse did not feel it was necessary to wear gloves.

According to my white participants, if someone in the white communities is HIV positive, that person will be excluded and regarded as inferior. They do not want to have anything to do with a HIV positive person. They will avoid that person because they are scared to be infected with the disease as well. When I asked my white research participants what they would do if they would be HIV positive, they answered that they would not disclose to their community or their partner because people would think she has been promiscuous. Furthermore, the women I interviewed would not disclose their status because of their children. They argued that their children would be targeted at school and even excluded from the community.

Thus, I can argue that stigma is both present in black and white communities. Both in black and white communities, women run the risk of being excluded and discriminated for being HIV positive. And both in black and white communities, women are regarded as promiscuous when they are HIV positive. The difference is that in black communities people are often uneducated about HIV/AIDS because they do not have access to means that provide education and in the white communities, people do not want to be educated about HIV/AIDS because they think the disease is only for black people.

5.1.4 What causes the stigma?

In South Africa, a lot of people are either infected or affected by HIV/AIDS.
“We are all affected by HIV. If we haven’t got it ourselves, we know someone who has or we have heard somebody has.” (director Bobbi Bear)

But even though HIV is a part of almost everyone’s life in South Africa, there is still a lot of stigma on the disease. There are a few reasons why there is such a high stigma on HIV in South Africa according to my participants. First of all, most of my participants argued that there is a strong stigma because of the way HIV was introduced. Some of these participants mentioned that in the early years of HIV, when Thabo Mbeki was president in South Africa, HIV/AIDS was denied by a lot of people, including the president himself. But when HIV was acknowledged as a problem in South Africa, the government introduced it as a disease for promiscuous people. Therefore, people are still afraid to disclose their status, because they think they will be labelled as promiscuous, even though they became HIV positive through blood contact or by being raped.

“When we learned about HIV before, we learned that HIV is contracted by a person who sleeps around. A person who sleeps with everybody. They’ve got that stigma that they shouldn’t be talking about their status because they will be labelled by other people that they have been sleeping around.” (counsellor Bobbi Bear)

Secondly, a lot of my participants argued that education in South Africa on HIV is only focused on the transmission. Therefore, a lot of people think that they will die once they become HIV positive, because they have only learned about how they can be infected with HIV. They have not learned about how they can still live a long life when they take their ARVs and live healthy. All of my participants argued that when women who have not received education on treatment are tested HIV positive, they see it as a death sentence. Probably, my participants all had professional or personal experience with women who were just tested HIV positive and did not have knowledge about the disease.

Finally, the last reason why the stigma is so high in South Africa according to my research participants is because people perceive HIV as a sexually transmitted disease only. That is also what education on the disease implies, they only focus on the sexual way of transmitting. Therefore, it is hard for people to talk about HIV or to disclose their status, because it is related to sexual intercourse, which, according to my research participants, is a sensitive topic to talk about, especially in Zulu culture.

“There are other ways the disease is spread, but a HIV positive person does not want to be associated with sleeping around and therefore keeps quiet.” (external counsellor)

This corresponds to what I observed. In one of the flyers I read that were distributed at an HIV/AIDS clinic I visited, there was only information on how to prevent yourself from HIV; abstain, be faithful
to one partner and use a condom. This confirms the emphasis on the sexual way of transmitting and probably explains why people do not want to talk about the disease and why people associate HIV with promiscuity.

5.1.5 The importance of knowledge

In this subsection, I want to emphasize the importance of knowledge about HIV/AIDS. Based on my participants’ view, it appears that knowledge about the disease is crucial for the existence of HIV/AIDS-related stigma. I will discuss how my research participants perceived the knowledge of the women they work with and the knowledge in the communities on HIV/AIDS.

I asked all of my participants if they think that the knowledge of women about HIV/AIDS is sufficient. It appears that the knowledge a woman has on HIV is very dependent on whether she received pre- and post-test counselling when she went for a HIV test. My participants argued that counselling is crucial for how a HIV positive woman perceives her disease and how she will plan her future living with the disease. As said before, a lot of women who are uneducated about the disease and go for a HIV test and receive the results without counselling, think they have received a death sentence. If a woman does receive pre- and post-test counselling, she will hopefully realize that there is still a future possible if she takes her ARVs, sticks to them and lives healthy.

The HIV/AIDS clinics I visited and where I conducted a few interviews, provide training for people who are recently tested HIV positive. During that training, they will learn everything about HIV/AIDS, how to live their life healthy and how to take their ARVs. In the clinics is also a lot of information available like pamphlets and flyers. But that is for women who get tested at a proper HIV/AIDS clinic. According to my participants, in a lot of government hospitals, there is no counselling provided for HIV positive people or people who get tested. And also, there is the large majority of people who do not get tested at all.

Bobbi Bear also provides education on HIV/AIDS. They have support groups for women on Fridays. Since 1994, women from the rural Ilovo community gather under a large tree every week. There, the director of Bobbi Bear and other Bobbi Bear staff members educate the women who come to that tree on HIV/AIDS, provide counselling and arrange HIV tests. Therefore, the women in the Ilovo community are rather educated on the disease.
Also, Bobbi Bear provides trainings at schools and in communities on HIV/AIDS. My participants argued that more women are educated on HIV now.

“I think that there is a majority that begins to understand that individuals are not given a life sentence by being infected with HIV/AIDS, that they can live a life normally with proper exercises, a proper diet, proper medication.” (counsellor Bobbi Bear)

But there are still a lot of women for who education on HIV is not available for and who do not have sufficient knowledge about HIV/AIDS. They are not fully aware of how HIV can be transmitted and how it can be treated. According to my participants, mainly in the rural areas, women are often uneducated about HIV. In rural communities, people often do not have access to education or to qualified counsellors. If a woman acknowledges she is HIV positive in a rural area, the chances of her being stigmatized more severely are a lot higher than in a more educated community. This is because people do not know about the disease and how it can be transmitted.

“In our rural communities women still get beaten out of their communities if they tested positive. Because the families and people in the community are afraid they are going to pass on the disease. Education is so important.” (financial director Bobbi Bear)

This view was expressed by more participants as they mentioned the lack of education as the source of stigma.

“They might be treated badly by people who do not know or are not knowledgeable about HIV/AIDS. That’s where the stigma comes from, people who are ignorant to what HIV/AIDS really is.”(counsellor HIV/AIDS clinic)
The lack of education on HIV/AIDS also led to people believing some very dangerous myths about the disease. The most notorious myth is the virgin myth. Bobbi Bear staff often had to deal with the consequences of this myth, as the myth has led to a lot of child-rapes and high HIV infection rates amongst children. Most of my participants argued that this myth is no longer going on, only in some very rural communities where the people often still believe in and rely on traditional medicine that supports these kinds of myths. But other participants argued that the myth is still going on, because they perceive the existence of the virgin myth as one of the causes of the high rates of child rape. Other, less but still dangerous myths were spread by government representatives. For example, the minister of health announced to the public that HIV/AIDS should be treated with vegetables like beetroots and garlic. Nowadays, according to my participants, rightful information about HIV is displayed by the government, but myths like that have affected uneducated people.

In subsection 5.1, I explained how people perceive the HIV/AIDS related stigma. Based on the outcomes presented in this section, I can conclude that even though the stigma seems to have reduced, or at least women with HIV are treated less hostile and violently, the stigma is still highly present. Women are often the victim of the stigma, as people associate HIV positive women with promiscuity. This is because a lot of people think the disease can only be transmitted by means of sexual intercourse. Furthermore, my research participants argued that the high infection rates and stigma can be reduced if people are more aware about the disease. Thus, education seems to be very important in reducing the stigma. In the final section of this chapter, I will explain more about methods to reduce stigma.

5.2 WOMEN AS VICTIMS OF HIV/AIDS-RELATED STIGMATIZATION?

When I started researching the topic of HIV/AIDS-related stigma in the communities where Bobbi Bear operates, I wondered whether it is different for a woman to be living with HIV than for a man. In my fieldwork, I noticed that it is different, very different. A lot of the difference comes down to gender inequality, therefore I will first explain how my participants perceived the inequality between men and women in general. Then I will elaborate on how this inequality translates into inequality in being HIV positive and into the stigma that is related it. Also, I will discuss the consequences of this inequality.
5.2.1 Gender inequality

When I asked my participants about the position of women compared to men in their communities, they all argued that women are unequal compared to men. Even though it is better than it used to be, because nowadays women are getting more independent and powerful because of education and because more women are working, women are still inferior to men.

“*There is of course major gender inequality. And it has changed, it is better than 50 years ago. But they are not up to the standards of a developed nation, not even close.*” (counsellor Bobbi Bear)

My participants argued that women are often subservient to their husbands. Men are seen as having more power than women. And in Zulu culture, some men are also polygamous. They have different wives and children from different women. But a woman ought to be faithful to one man. When I asked my participants how this inequality can be seen in the communities, they argued that it can be seen in that women are responsible for the children and household and that women have to be obedient to their man. Another expression of inequality according to my participants is that men often demand sex without a condom and the woman has to obey to that, even though the man has been sleeping with other women. This is also related to HIV prevalence rates as, obviously, unprotected sex leads to more HIV infections.

“*Women’s equality is a different thing, but it is very connected to HIV. Cause women don’t feel that they have the right to ask their husband to wear a condom. Women don’t feel that they have the right to exercise control over their own reproductive system.*” (employee other NGO)

My research participants argued that women are scared to demand protected sex, because then her husband will think she has had affairs. Women are often seen as possessions by men and therefore men feel they have the right to demand sex from their wives.

Another expression of inequality between men and women is the extremely high number of rape in South Africa. According to my research participants, this especially happens in black communities, where women are seen as having no rights. I also observed that a lot of the women I met or talked to have experienced sexual violence in their life, either dealing with raped women in their daily work or having been a victim themselves. One of my research participants who is member of the parliament and is chairman of the ACDP (African Christian Democratic Party) recalled stats from a research on high school boys that her party had completed.
“So you still have that situation in where boys think that it is fine to rape women. And I think it was 25 percent of the boys we interviewed that said they had raped someone. And the half of that group said that they raped more than once. High school boys.” (politician)

One of the women I interviewed who used to be an activist mentioned the cautionary rule. That rule implied that if a woman declares that she is raped and the man says he did not do it, and if there is no evidence, the credibility of the rape victim is questioned. The cautionary rule assessed a man as more credible and the testimony of a raped woman as untrue.

The inequality of women is also reflected in HIV-related issues. In the next subsection I will explain more about the difference between men and women in living with HIV.

5.2.2 HIV inequality and the stigma

I asked my participants if they think it is different for a woman to be living with HIV than for a man. Some of my participants, particularly my participants who work in a HIV clinic, argued that you can see the difference in that women are more open about HIV than men. Women are more likely to talk about their (HIV) problems and visit a HIV clinic than a man. My participants argued that men are too proud to talk about HIV or to get tested. Another difference is that women have more concerns when they are HIV positive. They often have children to take care of, they have to worry about their unborn child being HIV positive as well and they have to think about what happens to their children once they have passed away.

Furthermore, if a woman discloses her status, she runs the risk of her partner leaving her. As discussed in the previous section, if a woman is HIV positive, she is often perceived as promiscuous. Also by her partner. The man often thinks that she has been promiscuous, even though she became HIV positive through blood contact by for example attending at an accident or she became HIV positive because her partner slept with other women. My research participants argued that for that reason, a HIV positive woman is often abandoned by her partner.

“ If I would come home and tell him (my husband) I was HIV positive, the first thing in his mind would be that I slept around. He wouldn’t think, that I just had blood test and the needle could be infected, it doesn’t occur to him that I got the HIV from a different source. The men in SA think, if you test positive you slept around. That’s the bottom line, that’s how they think.” (counsellor Bobbi Bear)

My participants argued that if a man is HIV positive, he often thinks he has been infected by his wife or girlfriend. During interviews and informal conversations, it was often mentioned that HIV is known in South Africa as a women’s disease. This is because of a rule implemented in 1996 that implied that all pregnant women had to get tested for HIV. Consequently, if a pregnant woman got tested HIV positive and she told her partner about the results, the partner would think she brought...
the disease home. Even though she contracted HIV from him. My research participants argued that that is probably the reason why in South Africa, people think women are the carriers of HIV. Because of the large number of pregnant women being tested HIV positive.

“And what I said about 1996, when they took our stats, it is not fair on the women. That we as a country blamed the black women. Purely because they got tested first.” (director Bobbi Bear)

The fact that a lot of people see HIV as a women’s disease has some very dangerous consequences. I will elaborate on these consequences in the next subsection.

It can be stated that HIV positive women face more stigma than men. Because a woman is perceived as promiscuous when she is HIV positive, her partner and family may chase her away. Also, the women are often the victim of discrimination and exclusion by their community. Furthermore, as explained before, people perceive HIV/AIDS as a women’s disease; they perceive women as the carriers of HIV. According to my research participants, a dangerous consequence of this is that if a man is tested HIV positive, he sometimes wants to take revenge on women. A few of my participants that have to deal with HIV positive men in their daily work mentioned that a lot of HIV positive men purposely infect women by having sex without protection or by raping them.

“The other day a guy came in for testing and he said if I find out that I am HIV positive I will go and spread it. I asked him why and he mentioned that he doesn’t get the virus from the tree. He got it from the girls, so he will make sure that the girls will get the virus.” (counsellor HIV/AIDS clinic)

When I found out about this rather disturbing fact, I asked more participants if they knew about this ‘revenge rape’. Almost all of them agreed that it happens. I heard a lot of stories that involved revenge rape, but I could not find proof of the occurrence of this kind of rape.

“I even saw an interview with a man, his face covered, he said on tv that he was very angry because he had HIV and he doesn’t think it is fair that a woman did this to him so now he is taking revenge on all women and he doesn’t care he sleeps around as much as he wants.” (employee other NGO)

In this section, I highlighted the inequality between men and women and how this is translated into HIV related inequality. Because women are seen as the carriers of HIV and because HIV positive women are perceived as promiscuous whereas men are allowed to have multiple sexual relationships, they face more HIV/AIDS-related stigma than men. Therefore, in the communities where Bobbi Bear operates and probably in every community in KwaZulu-Natal, women are more often the victim of HIV/AIDS than men. In the final section of this chapter, I will elaborate on this gender inequality in relation to how the stigma can be reduced.
5.3 MANIFESTATION AND CONSEQUENCES OF THE STIGMA

In this section, I will present in what ways the stigma can be seen and I will discuss some of the consequences that derive from the stigma on HIV/AIDS. Based on my own experiences and observations, the stigma is mainly manifested through the secrecy and not-disclosing of the disease. I also talked to people who had experience with women who did disclose their HIV positive status and were stigmatized. In the following subsection, I will elaborate on how the stigma is manifested. Then, I will discuss the medical, social and psychological consequences of the stigma. The stigma has major consequences that not only affect the individual, but also society as a whole. I will elaborate on that in the second subsection.

5.3.1 How the stigma is manifested

The degree of the stigma and the way the stigma is manifested often depends on the community. The stigma can be seen in that women find it very hard to disclose their status, because of the possible consequences of disclosing their status. Therefore, a lot of women keep their status a secret.

“It’s really difficult for them to disclose their status to the entire community, because there is still that stigma thing. Others they don’t even disclose it to their families, because they know if they tell them they will stigmatize them. There are many cases when they came to me and said you know what I disclosed my status to my family and then they chased me away.” (counsellor HIV/AIDS clinic)

Three of the five research participants I did a focus group with, argued that they would not tell anybody if they are HIV positive because they are scared that people would think they have slept around and would throw them out of the community. The two other participants of that focus group argued that they would want to disclose, but eventually they would keep it a secret because otherwise their children would be targeted.

Because HIV positive women want to keep their status a secret, they often visit a clinic that is not in their own community. This is because they are afraid to run into somebody from their community and then their secret is revealed. My research participant who is the manager of a HIV/AIDS clinic mentioned that a lot of the people coming into her clinic are not from the community where the clinic is located.

My participants mentioned that some women do not want to get tested because they are afraid to run into somebody they know. HIV positive women and family members who do know often try to keep the status a secret. Even if a woman has deceased because of the consequences of AIDS, the family will tell the community she has died of TB or pneumonia. This in fact can actually be true,
as TB and pneumonia are often the causes of death when someone has advanced AIDS. But the family will not tell she was HIV positive.

As stated before, women who disclosed their status are sometimes excluded from communities and even from their own families. And if they are not excluded or chased away, my research participants argued that the stigma can be seen in that people do not want to sit next to HIV positive women or touch them and do not use the same toilet, plates or cutlery. In some cases there is also name calling, but according to the participants I discussed this with, extreme expressions of stigma like calling names and physical violence nowadays only happen in very rural communities. My participants argued that gossiping is another way of how the stigma is manifested. If a woman has disclosed her status, people in her community will start gossiping about how she got infected and will talk negatively about her because they think she has been promiscuous.

Thus, according to my participants, keeping the status a secret, exclusion, visiting medical facilities far away from their own communities, discrimination and gossiping are common manifestations of the HIV/AIDS-related stigma. Name-calling and physical violence aimed at HIV positive women are expressions of the stigma that happen to a lesser extent. In the next subsection I will describe the consequences of these manifestations of the stigma, according to my research participants.

5.3.2 Consequences of the stigma

The stigma on HIV that women have to face has consequences. Some of the consequences I already mentioned, as the stigma leads to women thrown out of their community, abandonment from their family and/or partner and their children targeted. These are direct consequences. But there are also consequences of the stigma that are not directly visible, but have a large impact on women and on society as a whole. In this subsection I will elaborate on these consequences.

As said before, a lot of women do not want to disclose their status because of the stigma. This leads to higher infection rates, as they would not have protected sex because they are afraid that if they use protection their partner will discover she has HIV.

“If I am HIV positive and I’m scared of talking about it to the guy. And when we have sex we not using condoms so that’s when the virus spreads. Because I didn’t disclose my status to that person and then the virus spreads.” (counsellor HIV/AIDS clinic)

“That is leading to the problem we are having now. A higher infection rate because nobody is telling.” (external counsellor)
Also, according to the research participants who work as HIV counsellors, women who are afraid to disclose their status often do not take their medication properly. Because they are scared that someone finds out they take ARVs or they do not know how to take their ARVs because they did not receive counselling. Furthermore, because women do not want to be seen in clinics by community members, they have to travel far to get to a clinic where they will not be seen by anyone they know to get their tests and medication. This probably makes it a barrier for a lot of women to receive treatment.

“With stigma people can’t reveal their status, they don’t disclose, they are not taking their medication properly. If they have HIV it can lead to full blown AIDS. Cause they are not taking their medication properly, they get opportunistic infections, which would then lead to high mortalities.” (manager HIV/AIDS clinic)

But my participants argued there are also a lot of women who do not want to get tested and know their status because they are afraid of what will happen if they are HIV positive. They are afraid to be abandoned by their partner or family and thrown out of the community. Also because some women see HIV as a death sentence, they rather not know their status.

“I think people don’t want to get tested because it is easier to not know.” (employee other NGO)

Obviously, not being tested has medical consequences. My participants argued that if women do not get tested and therefore not receive any treatment, the chance to get AIDS and die because of it is a lot higher. And of course, the virus will spread because if women are not aware of their status, they will infect more people.

“And from one individual we get 20 infected. Because of stigma. Period. Because of not disclosing their status.” (counsellor Bobbi Bear)

Another consequence often mentioned by my research participants is that women who have to face the stigma feel very lonely. If a woman has no one to talk to about her disease or if her partner and family members abandoned her, she can feel very isolated and become depressed.

“They don’t really have anyone to talk to and discuss how are they feeling and how the medicine is making them feel, about their symptoms. That’s a journey they have to take alone. If there was no stigma they would be able to have friends and speak about it openly.” (police officer)

“A lot of individuals that have HIV/AIDS become depressed. Because how they are socially going to be treated.” (counsellor Bobbi Bear)
The depression that befall women who are HIV positive and have to face or are afraid of the stigma can lead to suicide. My participants mentioned that they know a lot of HIV positive people who committed suicide. Probably, the combination of the stigma and the fact that a lot of people see HIV as a death sentence leads to high suicide rates.

“People are killing themselves. Suicide. That’s why. Because people see it as the end of the road.” (counsellor Bobbi Bear)

High mortality, infection and suicide rates are some of the consequences of the HIV/AIDS-related stigma that I discovered during my research. This suggests that the consequences of the stigma are severe, whether a woman does disclose her HIV positive status or keeps it a secret. In the next section I will explain how the stigma can be reduced, and hence, the consequences of the stigma.

5.4 INTERVENTIONS TO REDUCE THE STIGMA

One of the most important questions I asked during my research was how my participants think the stigma can be reduced. The participants I interviewed had different backgrounds; I interviewed a lot of counsellors and psychologists, but also a police officer, HIV activists, a politician and directors of Bobbi Bear and of other NGOs. Their different backgrounds and expertise led to a variety of methods on how the stigma can be reduced. However, most of these research participants argued that despite all of the efforts to reduce the stigma, the stigma will probably never go away entirely.

In this section, I will elaborate on the different methods to diminish the stigma as perceived by my research participants. But first, I will describe what my participants argued that women who have to face the stigma need the most. I think this is important to pay attention to, because the approaches to help women will also create more understanding and awareness of the disease, which might lead to reducing the stigma.

5.4.1 How to help women who face the stigma

A question I asked every participant during an in-depth interview was what do they think that women who have to face the stigma need. Almost all of the persons I interviewed for this research have to deal with women who are HIV positive and have to face the stigma. So I wondered what these women, from the different perspectives of my participants, need the most.

Counselling is seen as something that women who are HIV positive need the most. Counselling was mentioned by almost all of my 20 interview participants as crucial in the acceptance
of the disease by a HIV positive woman and her family. As argued before, pre- and post-test counselling is an obligatory part of HIV testing in most clinics, but often this does not happen properly or it does not happen at all. Therefore, women do not know what to do when they are tested positive, which leads to severe consequences as discussed in the previous section. My participants argued that if a woman who goes for testing receives pre-test counselling and is tested negative, she has received some information about the disease which increases her knowledge and reduces her prejudices about HIV/AIDS. And if a woman does get tested positive, it is very important that she knows what will happen now, how to take her medication and so on. It will make her feel more secure about her future, because she realizes that she does have some control on what will happen to her physically. According to my participants, counselling will also help a woman to feel more secure about facing her partner and family, because now she can explain to them what she knows about the disease; how the disease is transmitted, that it is not a death sentence etcetera.

Some of my participants who themselves are counsellors often emphasized the importance of secrecy in their work. Because of the stigma that is still going on, women want to keep their status a secret. Therefore, it is important for women to know that they can go to a counsellor for testing or counselling without their status being revealed. In that way, women can still receive the information and counselling that they need. Support is mentioned by all of my participants as something that HIV positive women need. They argued that if a woman is HIV positive, it is important that she receives support from her family and partner. But in some cases, because of the stigma, that is not possible. Either the woman does not tell her partner or family or they chased her away. Therefore, support groups where HIV positive women can talk about their disease together is very important.

“Support structures, and friends, which they (HIV positive women) don’t have. If I look at the lady in my building a lot of people don’t want to be friends with her cause she is HIV positive.” (police officer)

My participants argued that a woman will feel less lonely if she has other women to talk to who face the same thing as she does. She will realize that she is not the only one and that there is a place where she can talk freely about what she is going through without being afraid of the consequences.

“Support groups, cause when you are tested positive they think I am all alone there is no one I can talk to. But when they are in a support group, they see that there are a lot of people living with this thing. I’m not alone, there are other people living positive about the virus and still progressing.” (counsellor HIV/AIDS clinic)

Four of my participants who are HIV counsellors mentioned that in their support groups for women who recently found out that they are HIV positive, they make use of women who are living with the
disease for a longer period of time as role models. These women can explain to the other women how to live with HIV, how to take their ARVs and how to deal with their family. That helps women to see that for them there is also a chance of living long and positively with HIV.

Bobbi Bear also helps women to deal with being HIV positive. They often have counselling sessions at the Bobbi Bear center. And, as said before, Bobbi Bear has a support group for women every Friday. During that support group, women are taught about HIV, they receive counselling and they talk to other women from their community about HIV. Also, Bobbi Bear brings HIV positive women to clinics to get their CD4 count tested or to get medication.

Other ways of supporting women who are HIV positive that were mentioned by my two of my participants are home-based care structures. Two other participants argued that women need help to plan and take care of the future of their children. This will probably also create more awareness as family members of HIV positive women come into contact with professionals working with HIV/AIDS.

In this subsection, I elaborated on the ways to support women. Support structures and counselling appear to be the most relevant approaches to help HIV positive women. Some of these approaches will also create more understanding of the disease in the social environment of the women. In the next subsection, I will present the methods to reduce HIV/AIDS-related stigma as perceived by my research participants.

5.4.2 How to reduce stigma

An important method to reduce the stigma according to a quarter of my participants is using role models. They argued that it is very important to have a woman who speaks publicly about being HIV positive. Other women can learn from her experiences and knowledge. It is important to acknowledge the disease. Others will realize that there are more women who are also HIV positive. My participants argued that it is important for that role model that other women can relate to her. For example if HIV positive women in the community disclose their status publicly, that will help to create the awareness that there are more women like them living with the disease.

“Encourage people to share their testimony. Because a lot of people think that they are the only ones who have HIV.” (college student)

According to my participants, the role models can also function as the example of that it is possible to live long with HIV. They can show women that you can live a long and healthy life even though you are HIV positive, by taking medication, eating healthy, exercising and so on. Because the role models are the ‘living proof’ of that.
Half of my participants also mentioned that the partner, family and children of HIV positive women should be involved during counselling sessions or support groups. My participants argued that it will create more understanding of the disease and of what women are going through and it will reduce the chance of families stigmatizing the women and improve the chance of the families supporting women. One of my participants who is a HIV counsellor told me that she often helps women who are HIV positive to deal with their families.

“I support that person and help her to disclose and talk with the family and help them understand what they are doing is wrong. Speak with them, teach them about HIV. They didn’t know that for example if we live in the same room with her we cannot get the disease.” (counsellor HIV/AIDS clinic)

Another way to reduce the stigma is to treat HIV/AIDS as a normal disease. This was argued by another quarter of my research participants. Because HIV/AIDS is such a sensitive topic and women who have the disease are stigmatized, it is very difficult to talk about it. Even though in South Africa a large proportion of society is HIV positive. But, my participants argued, if HIV is treated like a disease that is incurable but treatable, just like for example diabetes, the stigma on HIV will reduce.

“But we go on and on and on about HIV. It’s just like diabetes. If you don’t take your insulin, you will die! HIV, if you don’t take your ARVs, you will die!” (director Bobbi Bear)

“A large proportion of society has it and no one is talking about it. It is part of our society people have it, like diabetes. It is a condition.” (employee other NGO)

According to my participants, this can start by doctors and counsellors talking about the disease in the same way as another incurable but treatable disease. Not acting like it is a death sentence and acting mysterious, but by openly talking about it. My participants argued that this will reduce the sensitivity and secrecy of disease and therefore reduce the stigma.

But the method that was most mentioned as reducing the stigma is education on HIV/AIDS. Almost all of my participants emphasized the importance of education for reducing the stigma. As said before, the stigma seems to derive from a lack of knowledge of HIV. But I wondered what should change in terms of education on the disease. Because there already has been a lot of money invested in education on HIV/AIDS. I wondered what would be the strategy to create awareness and knowledge about HIV so that the stigma would reduce. As stated in the first section, the education on HIV was mainly about how to prevent becoming HIV positive and especially on how to prevent becoming HIV positive by using condoms or abstaining.
“The education here in South Africa is on; it’s a horrible disease and how to protect yourself from it. Use a condom, protect yourself from the horrible virus called HIV.” (external counsellor)

Therefore, a lot of people in South Africa think that you can only get HIV by sexual intercourse and they associate HIV with a death sentence, which increases the stigma on the disease. My participants argued that education should be focused on treatment, so that people in South Africa will realize that a HIV positive diagnosis does not necessarily mean a death sentence. Education on the disease should include more information on what to do once someone is diagnosed HIV positive, more information on ARVs and on how to live a healthy life.

“That is where I would start, treatment literacy, teaching the communities and people all over South Africa it’s not a death sentence.” (financial director Bobbi Bear)

Also, my participants argued that education should emphasize that HIV is not just a sexually transmitted disease. More attention should be paid to other ways of transmission, like blood contact or breastfeeding. Probably, this will also improve equality between men and women, as the label on HIV positive women that they have been promiscuous will fade. And based on the outcomes presented in my second section on gender inequality, I also think that education on HIV/AIDS should emphasize the fact that women are not the sole carriers of HIV. This was not particularly mentioned by my research participants, but this will probably reduce gender inequality in the context of HIV/AIDS.

A large part of my participants argued that there should be more education on HIV/AIDS in rural communities. Especially in rural communities the stigma is very high. A lot of people in very rural communities do not have access to education on HIV and they sometimes still rely on traditional healing practices or believe in myths on HIV/AIDS. Thus, when a woman in such a rural community is HIV positive she will not only be stigmatized but also does not have access to medical facilities for testing and for receiving ARVs. Therefore, my participants argued that there should be more education on HIV/AIDS provided in rural communities where the lack of knowledge about HIV/AIDS is very high. Furthermore, the education should be provided in the language of that community, as a lot of people in very rural communities cannot speak English. It is also important that the community is involved when education is provided on HIV.

“The community should be involved in education on HIV because they are the people who interact with it on a daily basis. If you get those similar mindsets spread across a community, it becomes more normal and more accepted. You get treated better.” (external counsellor)
My participants argued that if more people in a community are involved in education on HIV, more people will be understanding towards the disease and towards the HIV positive women in their community.

I do agree with my participants when they argued that the stigma on HIV/AIDS will probably never go away entirely. But I think that a combination of the above mentioned methods, for example using role models to provide information about HIV/AIDS with the emphasis on treatment, will help to reduce stigma. Also, I think that it is very important for communities to acknowledge that it is not just a sexually transmitted disease and that women are not the sole carriers of the disease. However, the unequal position of women in general is underlying the fact that women have to face more stigma when they are HIV positive than men. Therefore, for women to become ‘equal in HIV’, I think that changes are needed on another level. Women need to become equal to men and only then they might not suffer from the prejudices that befall a HIV positive woman. But for now, if these interventions are applied in the communities of KwaZulu-Natal, South Africa is one step closer to reducing the stigma.
6. Conclusion

6.1 THE RESEARCH

Arriving at the end of this thesis, I will provide an answer to my main research question. I will do this by analyzing the answers on my sub questions in combination with my theoretical framework. This will lead to the final answer on my main question. First of all, I will start with a reminder of the research questions. The main question of this research was:

*How do the actors involved with Bobbi Bear perceive HIV/AIDS-related stigma on women in the communities where Bobbi Bear operates and how do they think the stigma can be reduced?*

The sub questions of my research were:
- How do actors involved with Bobbi Bear perceive the stigma on HIV positive women?
- Why are HIV positive women often the victim of stigmatization?
- How does HIV/AIDS-related stigma on women manifests itself in the communities of the actors involved with Bobbi Bear?
- What are the consequences of the HIV/AIDS-related stigma on women?
- How do the actors involved with Bobbi Bear think HIV/AIDS-related stigma on women can be reduced?

Before starting this research, I wondered if the stigma on HIV/AIDS has influence on the prevalence and mortality rates of the disease, if the stigma has inhibitory effects on overcoming HIV/AIDS in South Africa. This motive has led me to investigate the stigma on women in the communities surrounding Bobbi Bear. I conducted my research in South Africa, at Bobbi Bear, an organization that aims to rescue children who are sexually abused and fights for their rights. Bobbi Bear is located in Amanzimtoti, in the province of KwaZulu-Natal. Bobbi Bear also aims to increase awareness about HIV/AIDS by providing education and training on the disease for children and in communities. They also organize support groups for women where the topic of HIV/AIDS is a central point of discussion. The methods I used for gaining data about the stigma on women were interviewing, focus-groups, observations and informal conversations and informal group discussions. The group of participants consisted of Bobbi Bear-staff members (mainly counsellors) and other professional actors who are involved with Bobbi Bear. In the next sections, I will provide the results of this research. First of all, I will answer the first part of the main research question by answering the first four sub questions.
After that, I will answer the second part of my research question by answering the fifth sub question. In these sections, I will analyze the data from my research with the theoretical perspectives that I discussed in the third chapter. After providing the answer on my main research question, I will shortly discuss the limitations of my research and provide a short reflection on my fieldwork with recommendations for further research. And finally, I will end this thesis with a policy recommendation for NGOs and other organizations that aim to reduce the HIV/AIDS-related stigma.

6.2 HOW THEY PERCEIVE THE STIGMA

The people I talked to and interviewed during my research told me their view on the HIV/AIDS-related stigma. They often described the stigma as the label that is put on a HIV positive person. These views on the concept of stigma correspond with how Goffman (1963), Parker and Aggleton and Genberg et al. view stigma. These authors also see stigma as labelling a person who possesses an undesirable attribute, in this case, HIV. The stigma leads to reducing the person who has HIV, to alienating, excluding or even ostracizing that person (Peter & Aggleton 2003: 14; Genberg et al. 2009: 2279).

In the surrounding communities of Bobbi Bear, the stigma on HIV positive women is quite high. Even though it is not as bad as it used to be, when women were killed or beaten for being HIV positive, women who have HIV and disclose their status to their families or communities are often treated differently. They are sometimes even chased away from their community or their family decides they do not want to be involved with a HIV positive woman anymore. Therefore, a lot of women decide to keep their status a secret. Poku (2005: 170-181) also argues that many people living with HIV/AIDS keep their status a secret, because people are afraid of the reactions from their community (Poku 2005: 170-171). Often, not only the woman who has HIV/AIDS is stigmatized, the family is also treated differently. My research participants told me that if a woman is not chased away from her family, the family often decides to keep her HIV positive status a secret. This corresponds with Poku (2005), who argues that families affected by HIV/AIDS are often stigmatized and therefore keep the prevalence of the disease within their family a secret (Poku 2005: 170-171).

If a woman is HIV positive, people often think it is her own fault. This is because HIV/AIDS is seen as a disease that only happens to promiscuous people. This corresponds with Barnett and Whiteside (2002: 66), Poku (2005: 74-75) and Simbayi et al. (2007: 1823-1824) who argue that HIV/AIDS is associated with risk behaviours and therefore it is considered an ‘immoral’ disease that happens to people who do not conform to social norms.

My participants argued that women are often blamed for being HIV positive. This is in line
with Duffy’s article (2005: 16-17); she states that even though women contracted HIV from their husbands, women are often abandoned or ostracized by her husband or family because they regard the women as promiscuous. It is argued by my participants that women are more often the victim of stigmatization than men. Reasons for this can be found in gender inequality. According to my participants, in their country, women are often unequal to men on various levels. South Africa is a patriarchal society and Jewkes et al. (2003: 125-127) state that this is reflected in both black and white communities. There is a gender power imbalance that can also be seen in sexual relations, which leads to women being more vulnerable for contracting HIV/AIDS (Outwater et al. 2005: 150). Women are not only at higher risk to be infected with HIV/AIDS, women are also more often and more severely stigmatized when they are HIV positive. My research participants argued that if a woman is HIV positive, she is regarded as promiscuous. In South Africa, men are allowed to be promiscuous, but women are not. Therefore, women are more harshly treated when they are HIV positive and run a higher risk of their partner and/or family leaving them. Duffy (2005: 16-17) agrees with this, as she states that even though a woman became HIV positive because she contracted HIV from her partner who had affairs with other women, the woman is often sent away or ostracized by her partner and family. In the theoretical chapter, I stated that most of the authors that wrote on gender inequality and HIV do not emphasize the strong relation between gender inequality and stigma. However, during my research, it appeared that there is a strong relation between these issues. Women are often the victim of stigma, because when they are HIV positive, they are perceived as promiscuous. Also, people regard HIV/AIDS as a women’s disease, a disease that is carried and spread by women. Therefore, because of the gender inequality, women face more stigma than men. Thus, the link between gender inequality and stigma appears to be quite strong in practice.

The stigma can be seen in various ways. One way how the stigma can be seen is that HIV/AIDS is a very sensitive topic to talk about, as I experienced myself when I had trouble finding people willing to participate in this research. This was also often mentioned by my participants and in line with the arguments of Gilbert and Walker (2010: 140), Poku (2005: 74-75) and Simbayi et al. (2007: 1823-1824), as they also state that HIV/AIDS is a very sensitive topic to talk about, because people relate HIV/AIDS with culturally sensitive and taboo issues. Other ways how the stigma is manifested as mentioned by my research participants, is through keeping the status a secret, exclusion and discrimination, gossiping and visiting medical facilities far away from their communities. Extreme manifestations of the stigma like name-calling or physical violence happen to a lesser extent according to my participants. Keeping the status a secret out of fear of the consequences of disclosing the status is also mentioned by Gilbert and Walker (2010: 144) and Carr and Gramling (2004: 35-38). Their studies show that their participants did not want to disclose their
status because they were afraid to be accused of promiscuity or to be rejected by people around them. Kalichman and Simbayi (2010: 573) also state that it is an expression of the stigma that a lot of people keep their status a secret. Furthermore, my research participants’ arguments correspond with the arguments of Skinner and Mfecane (2004: 159-161) and Mahajan et al. (2008: 4-5) as they mention that exclusion, distancing from HIV positive women and discrimination are expressions of the stigma. The only manifestation of the stigma as argued by my participants that was not mentioned in the literature is that women often visit medical facilities far away from their own communities.

Consequences of the stigma occur on multiple levels, not only on individual but also on societal level. According to my participants, the stigma leads to higher mortality rates, because women fall sick earlier because they perceive HIV/AIDS as a death sentence or because the women not disclose their status because they are afraid of the stigma. This is also argued by Poku (2005: 150-151), as he states that the most dangerous consequences of HIV/AIDS-related stigmatization are the psycho-social and cultural constraints HIV positive people have to deal with for getting tested and receiving treatment. My participants also argued that the stigma leads to higher infection rates. This partly corresponds with Mahajan et al. (2008: 8) who argue that stigmatization can lead to increased transmission risk behavior because HIV positive people do not want to reveal their HIV positive status. But according to the arguments of my participants, this particular fear of a woman disclosing her status to her partner also has to do with gender-related aspects. A woman does not want to ask for protection during sexual intercourse because she is afraid her partner will accuse her of promiscuity. Furthermore, high suicide rates are also a consequence of the stigma mentioned by my participants. This corresponds with Wingood et al. (2008: 239) and Simbayi et al. (2007: 1823-1830), who argue that the stigma leads to a sense of isolation and depression that leads to a higher chance of HIV positive women committing suicide. In the theoretical chapter, I wondered if the secrecy that was often mentioned by the authors that I discussed, was in practice also an important part of the stigma. Based on the above mentioned results, it appears that in practice, the secrecy is also a strong manifestation of the stigma that has many consequences.

Consequently, this answers the first part of my research question. My research participants, the actors involved with Bobbi Bear, perceive the HIV/AIDS-related stigma on women in the communities where Bobbi Bear operates as the label that is put on HIV positive women. This label serves to reduce the woman who has HIV, ostracize her, discriminate her or even chase her away. My participants feel that the stigma is not as bad as it used to be, but that there is still a high stigma on HIV positive women in the communities where Bobbi Bear operates. Also, they argued that women suffer more HIV/AIDS-related stigmatization than men, this is highly related to gender inequality. The stigma is manifested through the sensitivity of discussing HIV/AIDS, through keeping the HIV positive
status a secret, exclusion and discrimination, gossiping and visiting medical facilities far away from their communities. My participants perceived the consequences of the stigma as severe, they argued that the stigma has consequences on both individual and societal level. Examples of the consequences are high mortality, infection and suicide rates.

6.2 HOW THE STIGMA CAN BE REDUCED

In this section, I will provide an answer on the second part of my research question. Based on the presented data, it can be stated that the stigma is a large barrier in overcoming HIV/AIDS. There are many consequences of the stigma that undermine efforts to reduce HIV/AIDS. During this research I wanted to find out how my participants think the stigma can be reduced. I considered it as very important to receive as much input from various perspectives as possible. Important methods to reduce the stigma as argued by my participants are using role models, involving the family of the HIV positive woman during counselling sessions or support groups and treating HIV/AIDS like any other incurable but treatable disease. The method that was most often mentioned as the best way to reduce the HIV/AIDS-related stigma is education on HIV/AIDS. Specifically, by putting the emphasis in education on treatment instead of on the ways of transmission. This will help to reduce the view that HIV/AIDS is equivalent to a death sentence. Also, emphasis should be put on the fact that HIV/AIDS is not just a sexually transmitted disease and on the fact that women are not necessarily the carriers of HIV. These last two focus points also touch upon the gender related aspects of HIV/AIDS and hopefully serve to improve HIV/AIDS-related equality between men and women. However, Campbell et al. (2005: 808) conclude that providing people with factual information about the contagiousness of HIV/AIDS is not sufficient to reduce the stigma. And Parker and Aggleton (2003) argue that the focus should be on group behaviour, because stigmatization is a social and cultural phenomenon linked to the actions of entire groups of people. This is in line with my research results, as it was also mentioned by my participants that there should be more education on HIV/AIDS in communities and especially in rural communities, in the language of that community. Kalichman and Simbayi (2004: 578) also argue that providing factual information on HIV/AIDS for people who hold traditional beliefs about the disease can reduce the stigma. Finally, my participants stressed that community involvement is important in order to create more awareness and similar mindsets when it comes to HIV/AIDS. In the theoretical chapter, there was not much agreement amongst the authors that argued for particular interventions to reduce the stigma. I wondered if my participants would provide perspectives on how to reduce the stigma that include elements that will create more understanding and awareness on multiple levels. Most of my participants argued that
education is the best way to reduce the stigma, however, they argued that the education should not only include factual information about the disease, but it should also serve to reduce prejudices about women and reduce the view that HIV is a death sentence. By example using role models to provide the education or by involving the community. Thus, these methods include various elements that will serve to reduce the stigma on multiple levels.

6.3 LIMITATIONS

During my research, there were some limitations I faced. For example the difficulty of finding people willing to talk openly to me about the stigma, ironically, because of the stigma. My first intention was to interview staff members of Bobbi Bear and women in the local community where Bobbi Bear operates. Because I experienced difficulties with arranging interviews with both staff members and women from the local community and because of other reasons I elaborated on in the methodology chapter, I eventually focused on the different actors involved with Bobbi Bear. This worked out for the best, as these actors all had different professions and backgrounds but all had to deal with women who face the stigma. Therefore, I gained various perspectives on the HIV/AIDS-related stigma and on how the stigma can be reduced. Furthermore, another limitation of this research was that I did not interview women who experienced the stigma themselves. But because all of my research participants work or worked with women who have to face the stigma, I obtained (second-hand) information about how women in the communities where Bobbi Bear operates experience and perceive the stigma.

6.4 REFLECTION

Overall, I feel that this research provided me and therefore people who will read this thesis with useful insights about the HIV/AIDS-related stigma. Especially because the stigma is such a large barrier in reducing HIV and because it has so many harmful consequences, I am happy to be able to contribute to both literature and practice on this topic. The latter, I will do in the next section. But what I can conclude from my research that might be useful for literature, is that researchers and authors should focus more on the link between gender inequality and stigma, as gender inequality plays an important role in the HIV/AIDS-related stigma on women. This is not done enough in previous studies and literature that has focused on gender inequality and HIV/AIDS. Furthermore, I think there should be more qualitative research on the topic of HIV/AIDS-related stigma, most of the articles I discussed are based on quantitative research only. From my own experience, I realize that it
is very hard to find someone willing to talk who actually has to face the stigma, but I think it can prove very valuable to have in-depth conversations to gain insights on how these people perceive the stigma. This can create a whole new level of knowledge on the stigma that can serve to come up with new interventions to reduce the stigma.

6.5 POLICY RECOMMENDATIONS

During this research, I gained many views from different perspectives on the HIV/AIDS-related stigma and on how this stigma can be reduced. This thesis hopefully can prove valuable to NGOs that aim to reduce the stigma on women who are HIV positive. My personal opinion is that more attention should be paid to the gender differences that are reflected in the stigmatization of HIV positive women. I do realize that this requires changes on a rather deep level. One starting point could be that efforts to reduce stigma should underline that women are not the sole carriers of HIV. Also, emphasis should be put on the fact that HIV is not just a sexually transmitted disease. This might help reduce the view that women who are HIV positive have been promiscuous and therefore became infected. Furthermore, education remains an important method to reduce the stigma, especially in communities where people are unknowledgeable about HIV/AIDS. But with implementing the aforementioned focus points and by highlighting the fact that HIV is an incurable but treatable disease, it might just create that little bit of awareness that is needed to reduce the HIV/AIDS-related stigma on women.


Gilbert, L. & Walker, L. (2010). My biggest fear was that people would reject me once they knew my status...: stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health and Social Care in the Community, 18*(2), 139–146.


