

People living with HIV and AIDS: An exploration of their positive and negative experiences in Health-Care Settings and whether it affects their Health-Seeking Behaviour

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DECLARATION

I declare that this research report is my own, unaided work. It has not been submitted before
for any other degree or examination at this or any other university.

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ABSTRACT

The present study investigated what kinds of experiences are being felt by eight people living with the Human Immunodeficiency Virus at the different health care sites that they frequent. It also explored the implications of both positive and negative experiences at health care settings for health seeking behaviour. The research was of a qualitative nature and data was collected through patient interviews which were semi-structured. Participants were sourced from an HIV and AIDS clinic at the *South African Trade Workers Union Worker Health Program* in Johannesburg, South Africa. After analysis, the results yielded showed that both negative and positive experiences were felt by people living with HIV and AIDS at their health care settings. The presence of negative experiences were mostly related to the lack of resources at the various health care settings. It was found that positive experiences were much more abundant than negative ones, and were found to be influenced by Doctor and Nurse support, and Personal Factors. It was found that the positive experiences did contribute to the participant's motivation to keep visiting their respective health care settings.

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CHAPTER ONE:

INTRODUCTION

1.1. Background and Context

The medical advances that were made during the late 1990's have altered the face of human immunodeficiency virus and acquired immune deficiency syndrome (HIV and AIDS) care quite dramatically. While being diagnosed with HIV was previously considered to be an effective death sentence, HIV and AIDS is now deemed to be much more of a chronic, manageable disease. Antiretroviral drug "cocktails," which include protease inhibitors and other anti-HIV drugs, have been found to reduce the amount of virus in many patients' blood to undetectable levels (Roberts, 2002). While the word "cure" is not being used in conjunction with these new advances, it is clear that these new treatment programmes are helping individuals to live longer and healthier lives (World Health Organisation, 2008).

In South Africa, the national antiretroviral treatment (ART) programme was launched in April 2004 (National Department of Health, 2003). The South African Government launched its five-year Strategic Plan for HIV and AIDS in 2000. This plan created the framework within which interventions aimed towards initiating and implementing an inclusive response to the epidemic were undertaken. The strategic framework identified four key areas of intervention, namely: (1) prevention; (2) treatment, care, and support; (3) research, monitoring and surveillance; and (4) legal and human rights (National Department of Health, 2003).

In April 2002, after reviewing its approach to HIV and AIDS, the South African Cabinet reiterated its commitment to the Strategic Plan. Having seen progress in the implementation of the Plan and the impact beginning to be made with regard to the prevention campaign, Cabinet decided on a number of measures to strengthen and reinforce these efforts. This included the acknowledgment that antiretroviral treatment can assist in improving the conditions and health of people living with AIDS if administered at certain stages in the progression of HIV. In accordance with international standards, government committed to continue its efforts to remove systemic constraints on access to these drugs. Furthermore, together with poverty alleviation and nutritional interventions, they were to encourage investigation into alternative treatments, particularly supplements and medication for boosting the immune system. Following the discussion of this report on 8 August 2003,

Cabinet instructed the Department of Health to develop a detailed operational plan on an antiretroviral treatment programme by the end of September 2003. In view of that task, the Minister of Health appointed a National Task Team on the 19th of August 2003, to assist in the development of a detailed operational plan (National Department of Health, 2003). This preceded the roll out of treatment programmes and access to anti-retroviral therapy (ART) for people living with HIV. These public HIV treatment programmes are continuing to expand and develop in South Africa. In relation to other countries around the world, access to these treatment programmes in South Africa is relatively new. It is therefore important to understand the mechanisms behind ART access, adherence, health, treatment experience, as well as, the consequences of treatment (Hirsch, 2007; Hirsch, Parker, & Aggleton, 2007 as cited in Fitzgerald, Collumbien & Hosegood, 2010).

Although the advent of antiretroviral therapy has greatly influenced the lives of people living with HIV and AIDS, the regimens are demanding and difficult, with many challenging side effects being possible. Patients also need to take their medication for indefinite periods of time. Essentially, if patients do not take their medications as prescribed, if they miss their doses or take them improperly, selected resistance is expected which leads to clinical failure of the medication (San Francisco AIDS Foundation, 1996; Ungvarski, 1997; Volberding, 1996 as cited in Roberts & Mann, 2000). With treatment and medication being made available to people living with HIV and AIDS means that numerous interactions with health care providers and visits to health care settings are to be expected. Health care providers in an HIV and AIDS medical setting will now have the opportunity to take on a valuable role in the supervision of the disease for patients. They could be turned to for providing education, assessment of disease status, direct medical care and medications. Furthermore, they can also be a major source of support (Bodenlos, Grothe, Whitehead, Konkle-Parker, Jones, & Brantley, 2007). The relationship between patient and health care provider as well as their interactions would therefore constitute a large part of the patient's experience at their health care settings.

1.2 Rationale

The prevalence rates of HIV in South Africa are unprecedentedly high. The number of people living with HIV in South Africa is now estimated to be around 5 700 000 (UNAIDS, WHO & UNICEF, 2008). Therefore any research that could lend more understanding to the nature of this epidemic would be invaluable.

Added to this is the fact that UNAIDS, in its 2008 report on the global AIDS epidemic, declared stigma to be one of the two most important factors to be considered, internationally, in relation to the prevalence of the disease. The other factor that increases HIV risk and vulnerability is gender inequality and the lack of empowerment of women and girls (UNAIDS, 2008). In 2006, in UNAIDS facilitated discussions, interested parties in 122 countries time after time acknowledged HIV-related stigma and discrimination to be one of the five main obstacles to attaining worldwide access to HIV prevention, treatment, care, and support (UNAIDS, 2008). This proves that not only is more research needed on HIV and AIDS itself, but particularly on the discrimination and negative experiences that surround the disease and the people affected by it.

One of the consequences of stigma that is experienced by people living with HIV and AIDS is the decline in health seeking behaviour. Stigma can result in lower medication adherence (Rintamaki, Davis, Skripkauskas, Bennet, & Wolf, 2006), reluctance to disclose HIV status (Nachega, Knowlton, Deluca, Schoeman, Watkinson, Efron, Chaisson, & Maartens, 2006) and can be a barrier to accessing voluntary counselling and testing (Daftary, Padayatche & Padilla, 2007). This clearly shows that there is a relationship between the presence of discrimination and health seeking behaviour. However, in South Africa the literature surrounding this topic is sparse. It therefore follows that research in the area of HIV and AIDS, stigma and health seeking behaviour is fundamental in broadening our knowledge on these topics.

1.3 Aims

Accordingly, the aims of this research were to explore experiences in health care settings of people living with HIV and AIDS and whether these experiences are positive or negative. The research also attempted to look at their HIV and AIDS related health seeking behaviour. If any sort of discrimination felt by the participants was to emerge as one of the negative experiences existing at any of these settings, the research would also then attempt to investigate whether there is a link between this and health seeking behaviour of people living with HIV and AIDS. In addition, the research also investigated the manner in which any positive experiences at the health care settings would result in strengthening attitudes towards their health seeking behaviour.

1.4 Summary of Chapters

In Chapter Two, a literature review is provided. Following this, in Chapter Three, an outline of the research methodology, including the specific research questions, is given. In Chapter Four a presentation and discussion of the research results is given. Finally, in Chapter Five, limitations and implications of the study are discussed and a conclusion is drawn.

CHAPTER TWO:

LITERATURE REVIEW

2.1 Prevalence of HIV and AIDS in South Africa:

It was reported in the 2008 report on the global AIDS epidemic, published by UNAIDS, that an estimated 1.9 million people were newly infected with HIV in sub-Saharan Africa in 2007. This brings the number of people living with HIV and AIDS to 22 million. These figures mean that two thirds (67%) of the worldwide total of 32.9 million people with HIV and AIDS live in this area, and three quarters (75%) of all AIDS deaths in 2007 occurred there (UNAIDS, 2008)

According to the Epidemiological Fact Sheet on HIV and AIDS, the number of people living with HIV and AIDS in South Africa is 5 700 000 (UNAIDS, WHO & UNICEF, 2008). The prevalence rate of adults aged 15-49 is 18.1%. There are 280 000 children aged 0 to 14 living with HIV and AIDS and 1 400 000 orphans aged 0 to 17 due to HIV and AIDS (UNAIDS, WHO & UNICEF, 2008).

2.2 Stigma and Disease:

2.2.1 Sources of Stigma:

Stigma has its foundations in ‘differences’. The anguish and emotional hurt experienced by the stigmatised person is connected to others’ pity, apprehension, revulsion and condemnation of this difference. This difference could be one of personality, physical appearance, illness and disability, age, gender or sexuality (Mason, Carlisle, Watkins, & Whitehead, 2001). Stigma can be defined as a quality that functions to discredit a person or persons in the eyes of others (Franzoi, 1996 as cited in Mason et al, 2001). The following is a definition from Goffman:

“While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted discounted one. Such an attribute is a stigma.”

(Goffman, 1990:12).

2.2.2 Sources of Stigma Related to HIV and AIDS

The experience of stigma has an extreme impact both in its emotional consequences for the person concerned and in its social effect for the marginalised group as a whole (Mason et al, 2001). With regards to HIV and AIDS, Carlisle (2001) suggests that it is the uncertainty that surrounds the cure for AIDS which continues to be a strong influence on the way in which HIV and AIDS psychologically affect those people who are infected and affected (family members and friends). The fact that there is no cure also impacts the way in which the virus is seen by society (Carlisle, 2001 as cited in Mason et al, 2001). Sontag (1991) maintained that the fear that can be provoked by diseases that have no cure, or which ultimately result in death, can generate emotional and behavioural reactions which are often not rational or reasonable in origin (Carlisle, 2001 as cited in Mason et al, 2001). One of these reactions which people with HIV and AIDS face is discrimination, and stigmatising public reactions are the result of complicated beliefs, many of which are entrenched in ideas and views around sexuality and sexually transmitted diseases (Carlisle, 2001 as cited in Mason et al, 2001).

Stigmatisation takes place because the disease is associated with sexually transmitted disease, with homosexuality, sex workers and intravenous drug users (Carlisle, 2001 as cited in Mason et al, 2001). Essentially, AIDS is seen as a consequence of what is commonly perceived as deviant and immoral behaviour (Gilman, 1988; Patton, 1990 and Sontag, 1988 as cited in Strebel, 1997). These reactions have meant that people with AIDS (PWA) are blamed, feared and shunned as opposed to receiving compassion and assistance (Strebel, 1997).

Strebel (1997) conducted a study in which fourteen focus group discussions were held. Two of these groups included men, while the rest were women only groups. There were ninety five black participants altogether, which were drawn from sexually transmitted disease clinics and antenatal clinics, community nutrition centres, women's and youth groups of a political organisation, domestic workers and students. Their ages ranged from fifteen to forty seven years, with an average of twenty six years. Two thirds of the participants had an African language as their mother tongue, while the rest spoke English or Afrikaans. The greater part of the subjects were single with at least some secondary level education, although roughly half were unemployed (Strebel, 1997).

Strebel found the following:

- AIDS was constructed as a silent and invisible disease.
- Due to the presence of a medicalizing discourse individuals are rendered powerless and dependant.
- The presence of a stigmatizing discourse which lead to the construction of blameworthy 'others'.
- Gendered discourses which result in the paradox of responsibility and powerlessness.

2.2.3 Consequences of Stigma and HIV and AIDS

In a study by Campbell, Foulis, Maimane, & Sibiyi (2005), the impact of social context on a participatory peer education programme was examined. This study involved young people in a peri-urban community in South Africa. It was conducted in Ekuthuleni in the KwaZulu-Natal province. They found that although HIV prevalence is high, levels of disclosure are very low due to the stigmatisation (Campbell et. al, 2005). They found a lack of critical thinking about the stigmatisation of youth sexuality, which was often referred to in judgmental language as 'bad behaviour', 'immorality', 'wrong-doing' and 'evil'. Few adults acknowledged the reality of young people's sexual desire, especially in relation to girls. Girls said adults had taught them to associate sex with shame and danger, rather than teaching them to be discreet about their sexual activities and to use condoms (Campbell et. al, 2005).

These studies show that there is little support or solidarity for people living with AIDS (PLWAs). The stigmatisation of HIV and AIDS often results in lack of support for AIDS sufferers by parents, teachers and the church (Campbell et. al, 2005). The stigmatisation of PLWAs, together with adult intolerance of youth sexual activity, makes many young people unwilling to associate themselves with HIV prevention efforts. Children are punished by their parents, school principals, and church leaders for attending HIV prevention programs (Campbell et. al, 2005).

Another study by Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo (2007) sought to investigate the prevalence of prejudiced incidences and internalized stigmas among 420 HIV-positive men and 643 HIV-positive women recruited from AIDS services in Cape Town. The premise behind this research is that socially constructed views of HIV and AIDS can be absorbed and internalized by people living with HIV and AIDS. It is possible that this internalization of stigma can lead to unfavourable emotional and behavioural consequences

(Simbayi et al, 2007). The results of this study showed that one in three persons with HIV and AIDS felt that friends and family had behaved differently towards them since testing HIV positive. Further to this, over 40% of participants had encountered discrimination since their diagnosis. Both men and women also reported self-depreciating beliefs regarding living with HIV and AIDS. These include feeling dirty, guilty and ashamed and that they were to blame for being HIV positive (Simbayi et al, 2007). The above studies show the importance of stigma in the psychological lives of people living with HIV and AIDS. What follows is a discussion of the behavioural effects that stigma has, with a focus on treatment seeking behaviour and levels of disclosure.

2.3 Stigma and Health Seeking Behaviour

2.3.1 Background

The drugs that are now available for the treatment of HIV do not cure HIV infection, however they do avert the development of AIDS. The drugs work in such a way that prevents the virus being made in the body, which in turn stops the virus from harming the body's immune system but they cannot completely remove HIV from the body. It is therefore important for people with HIV to continuously take antiretroviral drugs (World Health Organization, 2008). The use of antiretroviral therapy in combinations of three or more drugs as treatment for HIV and AIDS has not only led to a great improvement in the health and well being of people with HIV and AIDS, but also to a longer lifespan. However it is essential for people living with HIV and AIDS to adhere to their medications stringently, which means taking them every day at the right time and in the right way. This is to ensure that the levels of medication in the body are maintained. This prevents the virus from becoming resistant to the medication (World Health Organisation, 2008).

2.4 Obstacles to Adherence/Health Seeking Behaviour

One of the obstacles to treatment adherence that has not been explored enough is the impact of social stigma (Rintamaki, Davis, Skripkauskas, Bennet, & Wolf, 2006). Stigma anxieties are informed by the following:

1. A person's knowledge of and manner towards both HIV itself as well as people living with HIV

2. A person's observation of how other people perceive HIV, and
3. A person's experiences of fear, bias or prejudice that has been aimed at oneself or at other people living with HIV

Rintamaki et al. (2006) conducted a study which attempted to assess the impact of patient concerns for social stigma on correct adherence to one's medication schedule. The study was conducted in the United States of America but had significant results and is therefore used in this proposal as an example of the effects of social stigma on medication adherence. The sample consisted of 204 people living with HIV who were receiving medical care (Rintamaki et al, 2006).

The results showed that 35% of the participants revealed a moderate degree of concern for stigma, and 21% reported high anxiety as a result of taking medication for HIV. Multivariate analysis was conducted, and a high degree of concern for stigma was the only statistically significant, independent predictor of non-adherence to one's medication routine (Rintamaki et al, 2006). This research reveals how anxiety over social stigma does not only affect a person's emotional experience with HIV infection but also medication habits and as a result can have an impact on the effectiveness of treatment as well as health outcomes (Rintamaki et al, 2006).

2.4.1 Social Support and Adherence

A study conducted in the Western Cape had similar results however this study focused more on treatment support systems that patients have chosen for themselves and how this support might have an effect on medication outcomes (Nachega et al, 2006). The authors also looked at the chief elements of support, including the social and material resources that are needed for encouraging treatment adherence in South Africa. By way of the research questions, the barriers to antiretroviral adherence that are present for people living with HIV were also identified, one of which was the stigma associated with HIV status disclosure (Nachega et al, 2006). This research was based on social influence theories, which propose that getting the maximum benefit out of a supportive relationship may result in more positive modes of adherence behaviour in people living with HIV (Knowlton, 2003 as cited in Nachega et al, 2006). In terms of stigma, one might suppose that an increased experience of stigma may be related to a lower incidence of good quality, supportive relationships in the patients' life, which in turn may result in decreased medication adherence.

Through focus groups with HIV patients and in-depth interviews with health care workers, the researchers were able to identify several key factors important in adherence. The aspect most pertinent to this research is the identification of the importance of effective treatment supporters. A treatment supporter is defined as being a person in the patients' life who would observe, assist and support the patient so that he/she would take their medication and daily (Nachega et al, 2006). These treatment supporters are especially useful in order to sustain long term adherence, especially after the first 3 months of treatment where patients receive high levels of clinical support. It was reported that family members are the most likely to be chosen as treatment supporters for people living with HIV. The main kind of family support identified was financial or material and instrumental, for example providing transport to the clinic. Some informants also stated that family members provided moral support (Nachega et al, 2006).

2.4.2 Non-disclosure and Adherence

The difficulty arises when people living with HIV are reluctant to disclose their status to family members for fear of stigma. The health care professionals interviewed in this research project revealed that disclosure of HIV status is a crucial step in activating effective treatment support (Nachega et al, 2006). However during the focus group, the patients conveyed a sense of reluctance toward disclosing their status. In one of the groups, 4 of the 6 participants gave the same reason for not wanting to disclose. This was fear that if family members knew their status, they would stand in the street and announce it to the neighbours. Another patient revealed that when she disclosed her status to her family members, she lost their support. She was under the impression that she would have financial and moral support from her family but instead her mother rejected her and turned her siblings against her (Nachega et al, 2006). The stigma linked to HIV and AIDS is therefore a significant factor to sustaining adherence due to the fear of disclosing to family members who could possibly fulfil the role of treatment supporter (Nachega et al, 2006).

A different study carried out in Kwa-Zulu Natal looked at the decision making process that occurs for HIV testing and serostatus disclosure by 21 patients who were hospitalized with multi/extensively-drug resistant TB (Daftary, Padayatche & Padilla, 2007). One of the themes that came out of the data analysis was experiences and perceptions of stigma and disclosure. The results showed that experiences of stigma and prejudice were noticeable barriers to voluntary counselling and testing (VCT). Several of the patients reported being

scared of being seen at HIV clinics. This anticipation of stigma took priority over the potential gains from treatment (Daftary et al, 2007). What is interesting to note in this study is that there were more occurrences of felt stigma than enacted stigma. Felt stigma refers to the fear of being discriminated against, whereas enacted stigma is the actual experience of being discriminated against. Felt stigma impels a person to isolate themselves from others due to the anxiety they feel about the chance of being stigmatized (Scambler, 1998 as cited in Daftary et al, 2007). It follows that there is a perceived fear of being prejudiced against and this perception in itself is enough to inhibit an individual from seeking health care.

The research that has been conducted in the area of stigma and health seeking behaviour is vast and consistently shows that either the fear of experiencing stigma or an actual experience of discrimination can have a significant effect on an individual's treatment adherence. However there are a number of gaps in the literature that have been identified. Firstly there is not a lot of information available about where the stigma that is experienced originates from or where it is perceived to come from. Especially in the South African context, there is not enough research being done on what is occurring at the health care settings that individuals living with HIV and AIDS frequent and whether there is felt or enacted stigma emerging at these environments. Connected to this is the question of what "health seeking behaviour" actually means for individuals living with HIV and AIDS and what these practices are made up of. Most of the research focuses on health seeking behaviour to be related to medication adherence. However there is little research carried out that examines the individual's perception of health seeking behaviour, what this behaviour signifies for them and whether stigma plays a role in their conceptualisation and utilisation of health services.

It is clear that stigma plays a role in both health related behaviour of people living with HIV and AIDS, by influencing levels of treatment adherence, as well as their psychological and emotional states. This type of interaction is indicative of a biopsychosocial approach. An explanation of this model and the manner in which it functions within the HIV and AIDS and stigma dynamic now follows.

2.5 Facilitators of Adherence/Health Seeking Behaviour:

2.5.1 Spirituality as a Facilitating Factor

The availability of anti-retroviral treatment for people living with HIV and AIDS has moved the focus of HIV and AIDS from an incurable illness to a more chronic disease. Infected

patients and their families have therefore had to create lifelong coping strategies. One pathway for dealing with their issues and possibly seeking help is through religion and spirituality. Along with the social aspect of religion, the belief systems that people incorporate into their daily lives may influence how they approach their medical care (Park & Nachman, 2010).

Two types of religious coping techniques have been identified: positive religious coping and spiritual struggle. Positive religious coping includes different methods that reveal a secure relationship with God, a belief in life's larger meaning, and a sense of spiritual connectedness with others (Pargament, Smith, Koenig & Perez, 1998). In a study by Trevino, Pargment, Cotton, Leonard, Hahn, Caprini-Faigin and Tsevat (2010), positive religious coping and spiritual struggle in individuals with HIV and AIDS was explored within a bio-psycho-social-spiritual model. Specifically, the study examined the cross-sectional and longitudinal relationships between positive religious coping and spiritual struggle versus biological, psychological, social and spiritual well-being in individuals living with HIV and AIDS. The study was conducted in the United States of America, but is believed to have important bearing on this research. Questionnaires were administered to 429 participants at baseline, and then again 12-18 months later.

Cross sectional analyses showed that positive religious coping was associated with positive outcomes, including great self-esteem and spirituality. Spiritual struggle was associated with negative outcomes, including poorer quality of life, higher levels of HIV symptoms and higher levels of depressive symptoms. Furthermore, the longitudinal analyses showed that participants who scored higher on the positive religious coping reported improvements in well being over time. One possible interpretation of these findings is that positive religious coping leads to greater well-being (Trevino et al, 2010).

In another study, the factors that influence the medication decision making of persons living with HIV and AIDS were explored (Russell, Bunting, Graney, Hartig, Kisner, & Brown, 2003). Participants were asked open-ended questions about what they perceived to influence their medication taking. In the category of *Cognitive and Emotional Facilitator Factors*, Motivation and Factors of Faith were included. Motivation was comprised of themes such as personal knowledge and attitudes. With regards to personal knowledge, participants valued their own knowledge of medications. Attitudes included fear/avoidance of dying, acceptance, will power, positive attitude, altruism, and desire to live and avoid AIDS. The category of

Factors of Faith included four themes, namely belief in medications, a belief in God and prayer, confidence and trust in their health care provider, which was an important facilitator of medication taking for some participants, and a belief in cure (Russell et al. 2003). Belief in medications was reflected in terms of medication prolonging life and delaying disease progression. A belief in God and prayer was described in terms of the importance of a spiritual life, reading the Bible, having faith in God and putting their life in God's hands (Russell et al. 2003). Here one can observe another example of religion and spirituality as being important facilitators to adherence.

2.5.2 Experiences of Health Care Providers/Health Care Settings:

Russell et al. (2003) also found that confidence and trust in their health care providers was an important factor for many participants in terms of facilitating their medication taking. Patients with HIV and AIDS are likely to have frequent interactions with health care providers during the course of their disease. Health care providers in an HIV and AIDS medical setting will have a significant role in the management of the disease for patients. They are responsible for providing education, assessment of disease status, direct medical care and medications. Furthermore, they can also be a major source of support. The health care visit may provide a chance for patients who might experience stigma because of their illness to discuss issues more openly. On the other hand, if a patient experiences discrimination in the health care setting, this may negatively impact the relationship with his or her health care provider (Bodenlos et al. 2007). In one study in the United States of America, it was found that 26% of a nationally representative sample of HIV and AIDS patients perceived discrimination in the health care settings (Schuster et al. 2005 as cited in Bodendos et al. 2007).

Research has been conducted on how attitudes toward health care providers related to care appointment attendance. Keeping scheduled appointments is an important part of a patient's health seeking behaviour and was therefore believed to be an important factor in the current research. It was found that positive attitudes toward health care professionals and larger social support networks were significantly related to appointment attendance in patients with HIV and AIDS (Bodenlos et al. 2007).

Another study, conducted in the United Kingdom, looked at the experiences of African immigrant women living with HIV and AIDS. Their ability to live positively with HIV and AIDS was found to be closely linked with their Christian faith as well as their experiences at

their health care settings (Ndirangu & Evans, 2009). Health services were represented as a safe social space, and were greatly appreciated as a source of advice and support. Eight women were interviewed using semi-structured interviews and they unanimously referred to the HIV services as their most commonly sought out source of support, advice, and care for their illness. The majority were particularly complimentary about the care they received. Negative experiences were expressed at being from their own general practitioners, and were represented as a need to feel accepted and treated like 'normal people with a 'normal' illness.

The satisfaction with their health care that was expressed seemed to be reinforced by the obvious contrast in health care services between their country of origin and the U.K. The participants described coming from situations where there is a lack of resources and where they have experienced stigma and discrimination – especially from health care workers (Ndirangu & Evans, 2009).

The women interviewed originated from other African countries, namely Congo, Malawi, and Zimbabwe, and were comparing their experiences from these countries to their new home country of the U.K. However these findings were considered valuable to be included in this literature review for two reasons. Firstly, they offer confirmation for the notion that experiences at health care settings will have an influence on health seeking behaviour for people living with HIV and AIDS. Secondly, by comparing their experiences, the participants offer insight into the treatment that is being sought in African countries and therefore provide motivation to further examine patients with HIV and AIDS' experiences at health care settings in South Africa. The findings indicated that non-judgemental, personalised health care plays a significant role in encouraging these women to access psychosocial support and appropriate HIV and AIDS services in the U.K. (Ndirangu & Evans, 2008).

One study that was conducted in South Africa looked at men's experiences of antiretroviral therapy in South Africa (Fitzgerald, Collumbien, & Hosegood, 2010). The research was carried out in Kwa-Zulu Natal, and looked specifically at the health, health behaviours and health care experiences of HIV-positive men who were enrolled in a rapidly growing rural district antiretroviral therapy programme. The study used data collected during in-depth interviews with men, as well as their family members and programme staff. Public HIV treatment programmes that give antiretroviral therapy (ART) continue to grow and develop in Africa. The premise of this study is based on this, and the fact that it is therefore important to

gain an understanding of how gender shapes ART access, adherence, health, treatment experience, as well as the consequences of treatment (Fitzgerald, Collumbien, & Hosegood, 2010). While the current research is not guided by gender requirements, this study was believed to be valuable in terms of gaining insight into the health behaviours and health care experiences that are currently being felt in a South African context.

The results most pertinent to this research study were those pertaining to the health care experiences, and therefore will be focused on here. The participants held strong beliefs about the behaviour of health service providers, specifically staff in the treatment programme. One of the most valued aspects of their experiences was that staff behaved in a professional manner and that they could be trusted to preserve confidentiality. These high expectations produced a potentially delicate relationship between male participants and staff, one in which men might promptly stop attending if they felt as if their trust had been broken or that they received an unsupportive reaction to their difficulties (Fitzgerald, Collumbien, & Hosegood, 2010). Although limited to men, this study shows how experiences at health care settings and the interactions that exist between patient and health care provider seem to be important features of the health seeking behaviour of people living with HIV and AIDS. These participants went so far as to report that they would stop their attendance at their health care settings if they believed they were not receiving sufficient support from their health care providers. It is therefore important to look at whether these sentiments are also held by women, and how greatly these experiences affect the health seeking behaviour of people living with HIV and AIDS in South Africa.

2.6 The Biopsychosocial Model:

The biopsychosocial model was developed by George Engel (1977) as a challenge to the medical profession to reconsider a strict biomedical approach to medical education and care. He argued that humans are biological, psychological, and social beings who act in certain ways that can either promote or damage their health. This means that there are many different dynamics at work, from the cellular to the social, and each of these factors can contribute to health and illness. The implication of this is that a disturbance in any area of human functioning will affect all the areas (Novack, Cameron, Epel, Ader, Waldstein, Levenstein, Antoni, & Wainer, 2007).

The biopsychosocial model represents an attempt to integrate the psychological (*psycho*) and the environmental (*social*) factors into the already established biomedical (*bio*) model of health (Ogden, 2004). The model proposes that all three factors affect and are affected by an individual's health (Sarafino, 2002). The factors that contribute to the *bio* element include genetics, viruses, bacteria and structural defects that are involved in health and illness (Ogden, 2004). Essentially, they are the aspects of a person's physiological functioning (Sarafino, 2002). The *psycho* aspects of health and illness are described in terms of cognitions (e.g. expectations of health), emotions (e.g. fear of treatment), and behaviours (e.g. smoking, diet, exercise) (Ogden, 2004). Finally, the *social* sphere is comprised of social norms of behaviour, pressures to change behaviour, social values on health, social class, and ethnicity (Ogden, 2004). By including psychosocial factors in the biomedical model, a treatment approach can be developed that acknowledges the human qualities of both the patient and the physician (Sheridan & Radmacher, 1992).

The biopsychosocial model is based on *general systems theory*. One of the fundamental assumptions of this theory is that systems exist within systems (Sheridan & Radmacher, 1992). A system is a dynamic entity that is comprised of components that are continuously interrelated. A person is viewed as being a system in itself, as well as part of other systems, such as his family, and society in which he lives. These systems all affect and are affected by each other (Sarafino, 2002). This approach compels researchers and practitioners to develop a global view of their work, which then emphasises the fact that interventions at one level of a system can often lead to unanticipated outcomes at other levels (Sheridan & Radmacher, 1992). Using the biopsychosocial model as a guide, researchers have discovered new and important findings and ways to promote people's health and recovery from illness such as using psychological methods to reduce anxiety, as well as the fact that people who have higher levels of social support from family and friends are more likely to have better health outcomes (Sarafino, 2002).

In a review of the literature on integrated HIV care Soto, Bell and Pillen (2004) found certain insights with regard to key elements of implementation and evaluation of integrated care. The one most pertinent to this research is the idea that the interacting biological, psychological and social needs of patients should be addressed simultaneously rather than as independent, isolated elements. Behavioural interventions and ancillary services which are co-ordinated with medical care are more responsive to patient needs and play a significant

role in promoting treatment adherence and improving health outcomes (Soto, Bell & Pillen, 2004).

In relation to this research, it may be suggested that both felt and enacted stigma experienced by people living with HIV and AIDS could be a social element that could affect or influence all other elements in the individual's life. As has been illustrated in the above studies, stigma plays an important role in treatment adherence of people living with HIV and AIDS, with higher levels of stigma leading to lower levels of adherence. Consequently, this has a negative effect on the person's health. The presence of stigma also affects a person's psychological and emotional well-being, as it is associated with less social support from family and friends. In terms of the biopsychosocial model, this shows the manner in which the three functions can affect and be affected by each other, with stigma being the social factor that affects the individual's physiological and psychological states. It therefore follows that intervening at the social level, by attempts to reduce levels of felt and enacted stigma, is likely to lead to changes in the physiological and psychological factors.

If it is understood how a variety of psychosocial factors interact to promote or maintain illness, interventions can occur at a variety of levels. It is no longer necessary or recommended to only intervene at a biological level but to include cognitive, behavioural and/or emotional features in treatment planning and understanding of health and illness (Novack et al., 2007).

CHAPTER THREE:

RESEARCH METHODOLOGY

3.1 Research Questions

The over arching research question investigated in this study is:

- What are the experiences of people living with HIV and AIDS in health care settings and how do these experiences affect their health seeking behaviours?

In an attempt to answer this general question, the following research questions were explored:

1. Do people living with HIV and AIDS have negative experiences in health care settings?
2. Do people living with HIV and AIDS have positive experiences in health care settings?
3. What are their HIV and AIDS health seeking behaviours?
4. Is there a link between these experiences and health seeking behaviour?

3.2 Research Design

This research was qualitative in nature, as it attempted to look at an individual's view of health seeking behaviour, and their experiences in health care settings. Qualitative research believes people to be complex language users, who have an ability to interpret and understand their own social worlds and experiences (Brown & Locke, 2008). It was therefore suitable for this research as a way of understanding the individual's conception of their behaviour and experiences. It is located in the interpretative phenomenological study, as this paradigm looks at a comprehensive investigation of individual lived experience, and how the individual makes sense of that experience (Eatough & Smith, 2008). This applies to this research, as all the research questions look at health seeking behaviour and experiences from the individual's point of view.

3.3 Data Collection

The methods used to collect data were semi-structured interviews. This type of interview is a steered, focused and open-ended form of communication between the interviewer and the participant (Crabtree & Miller, 1992 as cited in Crabtree & Miller, 1992). This method of interviewing allows the researcher to examine events from the participant's perspective;

his/her experiences, insights into and explanations of events (Johnson, Williams & White, 1992 as cited in Crabtree & Miller, 1992). It also allows the interviewer to have a clear idea of the kind of information he/she wants to elicit, whilst providing room for improvisation at the actual time of interviewing.

Since this topic looks at people's experiences and their perceptions of treatment at health care settings, it was necessary to be able to gain their own subjective opinion on the matter. The research also attempted to discover the conceptualisation behind the term *health seeking behaviour* from the perspective of an individual. In other words, it was hoped that a clear understanding would be gained of what the term means for a person living with HIV and AIDS instead of looking at it from a medical perspective. Once again, the individuals' own, subjective experiences needed to be gathered. For these reasons it appeared that the most suitable method of data collection would be semi-structured interviews.

This is also a very sensitive topic, which would have made other forms of data collection, such as focus groups, difficult, as individuals may have felt uncomfortable revealing this type of information whilst in the presence of others. Interviews were also deemed to be the best way to acquire information if a translator needed to be utilised as there would be only one person's response to translate at a time. This would avoid confusion and the possibility of neglecting important parts of the participant's discourse. It is for these reasons that semi-structured interviews were believed to be the most suitable method of data collection for this research topic.

After the initial day of interviewing, it was found that the level of English of the participants did not seem to be adequate enough for the gathering of sufficient information. Due to time constraints and the logistics of the group, it proved to be impossible to re-do the interviews with a translator. Instead, short questionnaires were drawn up and translated into three languages, namely Zulu, Tswana, and Sotho (Appendix G). A second day was arranged to administer the questionnaires. The idea was to translate these into English and to use the answers as supplementary data to the initial interviews. However, given the time constraints mentioned above this proved to be difficult and it was decided that the initial interviews had yielded enough data to gain a broad understanding of the research questions, if not an in depth examination.

3.4 Participants

The sampling technique used was a non-probability purposive technique, as there were certain criteria that needed to be met in order to be included in the study, but the participants had to be available and willing to participate in the research.

The participants interviewed were a group of people who are living with HIV and attend the HIV support group at the *SATWU Worker Health Program*. As the participants were all people that already attended the HIV support group, this guaranteed that the patients being interviewed were in fact living with HIV and AIDS. The participants were already known at the clinic as living with HIV and AIDS. The sister in charge was approached, and stated that she would personally explain the purposes of the research to the patients individually. The participants have all been on treatment, meaning they all were currently on a course of antiretroviral therapy for a duration of one year on average. This was to ensure that information could be gathered on all the variables from all the participants. It was hoped to find participants that had attended the clinic for at least three months. Research shows that patients receive high levels of clinical support in the first three months of treatment and after that it begins to drop (Nachega et al, 2006). The sample consisted of 8 participants aged between 27 and 44 years. This was to ensure that they would be old enough to articulate their experiences. Unfortunately the sample consisted only of women, as there were no men attending this particular support group. This meant that gender bias could not be controlled for.

Contact was made with the Managing Sister at the *SACTWU Worker Health Program*, which is the clinic at the South African Trade Worker's Union, regarding gaining access to the clinic in order to find individuals willing to participate in the research. Access at this clinic was granted and permission was given to conduct interviews with the patients that attend the clinic (Appendix B). The interviews were tape recorded and transcribed in order to aid data analysis.

3.5 Procedure

The clinic used provides free medical care for all workers in the garment industry. Information letters detailing the purpose and procedure of the study were sent to the relevant directors (Appendix A). The manager of the clinic granted permission for the researcher to conduct interviews with the patients attending the clinic for HIV and AIDS related treatment

(Appendix B). After permission was granted, the researcher personally approached the staff at the clinic, to discuss the recommended ways of approaching patients. The sister in charge stated that she would approach patients individually to explain the purposes of the research. Once ethical clearance was obtained, the researcher then approached patients individually with information letters (Appendix C) that detailed the purposes of the study. This was done in person in order to allow the patients to ask questions regarding any matters they were unsure of. Once a patient agreed to participate in the study, they were provided with and required to sign informed consent forms for interviewing (Appendix D) as well as for tape recording the interviews (Appendix E). At this stage it was still believed that an interpreter would not be required. The research was then conducted on a day when the participants were attending the clinic for their support group, in order to ensure convenience.

The interviews followed a semi-structured interview schedule (Appendix F). Each interview took approximately 30 minutes to complete. Once the interviews were concluded, counselling services from the Emthonjeni Centre at the University of the Witwatersrand were offered to the participants in case they became emotionally upset by the interviews. None of the participants felt they needed any counselling after the interviews.

3.6 Ethical Considerations

To ensure that this research was ethically sound, certain measures had to be taken. Due to the fact that this research dealt with HIV and AIDS, ethical clearance was obtained from the University of the Witwatersrand Medical Ethics Committee (Protocol Number: M10241). Once this had been granted, the appropriate steps were taken with the SACTWU Worker Health Program in order to carry out research at their HIV clinic. These steps were detailed in the section above, under the title “Procedure”.

3.7 Data Analysis

When using thematic analysis, specific themes, issues and repeated topics within the issues can be isolated, added up and interpreted from the text (Frey & Fontana, 2003 as cited in Denzin & Lincoln, 2003). Due to the nature of semi-structured interviews, it was possible that the responses obtained from the participants would not correspond directly to the issues being addressed. It was therefore necessary for the researcher to pull out major themes from the responses to see if a pattern existed or not.

This thematic analysis was deductive. This means that the analysis was focused by the researcher's interest in the area being explored. This type of analysis provided a more comprehensive explanation of some feature of the data. When deciding between inductive or deductive analysis, thought must be made to the aspects of how and why you are coding the data. If one is coding for a specific research question, it falls into the deductive area (Braun & Clarke, 2006). Since this research is coming from a theoretical point, with specific research questions, it was analysed deductively.

Thematic analysis consists of a number of steps that must be carried out in order to complete the process (Braun & Clarke, 2006). What follows is a brief description of each step that was carried out by the researcher once the data had been collected.

1. Familiarising self with the data – the data was transcribed, which was a significant part of the familiarisation process, and then read and re-read in order to become fully acquainted with the material. Initial notes were also taken down in this stage.
2. Generating initial notes – interesting features of the data that were significant to the study were then put into codes in a methodical manner.
3. Searching for themes – the codes generated in the second phase were then put into possible themes, and all data that was relevant to these themes was gathered. This was the beginning of analysing the codes that were identified.
4. Reviewing themes – in this stage, the themes were refined to fit in with both the coded extracts and the entire data set. Certain themes were expanded, cancelled, or meshed together.
5. Defining and naming themes – the analysis continued to further review the specifics of the themes pulled out and the overall account of the analysis.
6. Producing the report – when the report was created, pertinent extracts were chosen in order to give examples and the analysis was linked to the initial research questions and literature (Braun & Clarke, 2006).

CHAPTER FOUR:

RESULTS PRESENTATION AND DISCUSSION

Thematic content analysis was used to examine and interpret the eight transcribed interviews that were conducted. From this analysis, three major themes were extracted. Within certain of these themes subcategories exist. These themes and subcategories were aligned with the research questions and aims of the current study. What follows is an in-depth presentation of these themes together with a discussion of their implications.

The themes and subcategories that emerged include:

4.1 Positive Experiences:

4.1.1 Counselling and Education services

4.1.1.2 Doctor and Nurse Empathy, Patience and Personal Interest

4.2 Negative Experiences:

4.2.1 Lack of resources

4.3 Personal Factors

4.3.1 Religion

4.3.2 Re-evaluation of Self in the Face of an HIV and AIDS Diagnosis

4.3.3 Dealing with the Fear of Stigma

4.1 Positive Experiences

All of the eight participants interviewed reported experiencing some kind of positive treatment at the health care setting they frequented. While these experiences differed according to each individual participant, certain common themes were drawn out. These were mainly centred on the general support that they felt they received from their doctors and nurses. This support can be broken down further into different types of encouragement. This

breakdown is necessary in order to identify the different areas in which the participants feel they are receiving support. It is for this reason that many subcategories exist within this theme.

4.1.1 Counselling and Education Services

These two subcategories were grouped together as it was felt that they comprised actual services that the participants felt they received from their health care settings or from their doctors/nurses rather than the positive treatment they receive.

Two participants spoke of the value of counselling they received at their health care settings. Participant C speaks of *voluntary testing and counselling (VCT)*. She said that “they counsel you first then they test you. After testing you then they give you the results”. This helped in reducing her fear of being treated differently at the beginning. She also reported that when she is feeling despondent she knows that she can go to the nurses for counselling:

“at home I know that when I go there I ask maybe nurses you know I’ve got a problem like this. They just counselling me, telling me no you mustn’t worry especially if you are in this situation you must just be positive. Don’t hurt yourself”.

Participant H explains how her counsellor at the hospital helped to arrange special treatment for her because of the medication she was taking. She takes tablets that make her tired and drowsy but because she works the nightshift she is forced to take these pills in the morning which is when she sleeps. This proves problematic for her as on her check up day at the hospital she is forced to stand in line feeling tired and drowsy:

“Ja, so when it’s my check up I must take it at 8 o’clock and I can’t skip. You feel drowsy when you take that one. So when I’m taking that one I must go to the clinic that day it is my check up day. I stand there in the line. I feel drowsy. So I explain to the counsellor, the lady who was counselling me at this time I’m feeling like this. He said no talk to a doctor. I spoke to my doctor. The doctor tell the nurse when this lady come always you must tell me as soon she came so then I can take her very quick so then she can go home”.

Obtaining education about their status and situation also seems to be quite valued by three of the participants. This service seems to increase their feelings of positivity towards their health care settings. Participant A says she “felt great because there are people who are accompanying us who are always talking with us how can we treat ourselves when you know

when you are HIV positive”. This refers to the provision of information on how to manage their illness within their day to day lives.

Participant C spoke more of the ability to ask the nurses about things that may be bothering her. She states that the nurses “are talking and me I’m talking too. If maybe I see something I do ask and they help that patient to also ask”. This account differs to that of Participant A in that it does not refer to the spontaneous provision of educational services. However it is felt that it falls under this category as the participant feels safe to ask the nurses for information on areas that may be bothering her. This relates to a positive experience as it enables the participant to gain an understanding of what she is going through, which in turn relates to education.

Participant G relates good treatment to education. She says that “they treat us nicely”. When asked to elaborate on this she explains that “they teach us about HIV ja and how to prevent HIV if you have HIV and how to care about yourself”. She also states that they tell her “you must eat this and this everyday”. She then goes on to say that it is this service that contributes to her wanting to go back to the hospital. Once again it is noted that the provision of helpful advice on how to live with their illness contributes towards creating a positive experience at the health care setting which Participant G visits.

4.1.2 Doctor and Nurse Empathy, Patience and Personal Interest

This was the largest and most meaningful category to come out of this theme. All of the eight participants interviewed gave actual accounts of how they had experienced some kind of understanding from their doctors and nurses, and felt that the doctors and nurses had time for them and their difficulties. Furthermore, accounts were also given from certain of the participants of how their doctors had taken a personal interest in their well-being. For all of the participants, these feelings of support had been a significant contribution to their experiences at their health care settings. Feeling that the doctors and nurses were available to them, encouraging them and could offer some understanding led the participants to have very positive experiences at their health care settings. This in turn encouraged them to keep returning for their checkups as they looked forward to the positive treatment they felt sure they would receive.

Due to the magnitude of this category, it was thought best to provide evidence of these feelings in the form of a table, offering the most significant instances from the data. The table provides the quotes as well as an example of what kind of support the quote illustrates.

<i>Table 1. Doctor and Nurse Empathy, Patience and Personal Interest</i>		
TYPE OF SUPPORT	QUOTE	PARTICIPANT
Encouragement	<i>They really encourage us all of them</i>	Participant A
Nice treatment	<i>They treat me nice; he is nice to me</i>	Participant B
Experience of understanding and empathy	<i>So far the nurses they understand us, they've got patience for sick people especially those who are HIV; I feel good when I go there because they understand us.</i>	Participant C
Encouragement and Patience	<i>They've got time for somebody. It doesn't matter whether they know you, doesn't know you. They're so friendly; a lot of people encourage me, they say to me come well.</i>	Participant D
Nice treatment	<i>I'm not scared because the nurses they're ok; they treating us, welcoming us; they just greeting us, asking us today you are going to this line;</i>	Participant E
Nice treatment and Personal Interest	<i>They treat me very well because if I've got problems I</i>	Participant F

	<i>tell them my problems then they treat me nicely; If you feel you are not better you must come back anytime then we'll do something else; it helps me keep going.</i>	
Nice treatment and Personal Interest	<i>they are very nice to me; they ask me how your treatment, how are you feeling;</i>	Participant G
Personal Interest	<i>When I have a problem he gave me the phone number to phone any time if I feel there's something I don't understand in my body I just phone. He tell me no take this and this; At X they are very so nice because they've got time for you.</i>	Participant H

From the above table, one can clearly observe the level of support that is being felt by the patients at their respective health care settings. They all reported a sense of understanding and time for their situations. Four of the participants directly related their answers to their HIV status. However the interview was structured in such a way as all the participants were speaking specifically about their HIV and AIDS related care. Therefore it is given that the above quotes are all related to the care they receive as part of their HIV and AIDS related treatment. As can be seen, these positive experiences encourage the participants to keep returning to their health care settings.

The term *treatment support system* has been used to describe a supportive system that exists in a patients' life that serves to observe, assist and support the patient so that he/she would take their medication daily (Nachega et al, 2006). A study conducted in the Western Cape focused on treatment support systems that patients have chosen for themselves and how this

support is a key factor in medication outcomes (Nachega et al, 2006). These treatment supporters are especially useful in order to sustain long term adherence, especially after the first 3 months of treatment where patients receive high levels of clinical support. It was reported that family members are the most likely to be chosen as treatment supporters for people living with HIV (Nachega et al, 2006).

This research was based on social influence theories, which propose that getting the maximum benefit out of a supportive relationship may result in more positive modes of adherence behaviour in people living with HIV (Knowlton, 2003 as cited in Nachega et al, 2006).

From the instances from the data laid out above, it is suggested that a patient's doctor or nurse could take on the role of treatment supporter; the supportive relationship could also be defined in terms of the relationship that exists between patient and health care provider. All the participants relayed how their doctors' support encouraged them to visit the clinic, which has a direct effect on their medication adherence and health seeking behaviour. It was the friendly encouragement and knowledge of their doctors' availability that most spoke to the participants in terms of their positive experiences at the clinic. These positive experiences in turn encouraged them to return.

A study in the United States of America showed that positive relationships with their HIV and AIDS health care providers were valued and resulted in a persistent ability for the patients to engage and continue with medical care (Rajabiun, Mallinson, McCoy, Coleman, Drainoni, Rebholz, & Holbert, 2007). Similar results are seen here where the participants place high value on the positive relationship they feel with their own health care providers. This in turn results in a positive feeling towards the health care setting they frequent. It follows that they would be encourage to keep returning since they have such positive experiences, as well as the fact that it lacks negative treatment.

The findings in the current study further support previous research that has been carried out which looks at the relationship between patient and health care provider for people living with HIV and AIDS, both internationally and in South Africa. Russell et al. (2003) found that being able to trust their health care providers led to higher adherence in people living with HIV and AIDS in the United States of America. Findings suggested that as patients have so much interaction with their health care providers, a trusting and supportive relationship greatly influences their medication decision making (Russell et al. 2003).

In a South African study, it was found that men with HIV and AIDS believed the behaviour of their health care providers and their experiences at their health care settings to be significantly valuable to their health behaviour. The participants in this study reported that unsupportive relationships and not having confidence in their health care providers may lead to inattendance at their respective health care settings (Fitzgerald, Collumbien, & Hosegood, 2010). The current research shows similar findings in relation to women. All the participants interviewed were women, and they display similar views in terms of the value they place on the relationship they experience between themselves and their health care providers. It seems that when a positive relationship exists, the participants feel stronger about their health care settings, and feel better about their status and medication taking behaviours.

Using the biopsychosocial model as a way of understanding the treatment of people living with HIV and AIDS means taking the biological, psychological and social factors in that person's life into account (Ogden, 2004). The model proposes that all three factors affect and are affected by an individual's health (Sarafino, 2002). The psychological (*psycho*) aspects of health and illness are described in terms of cognitions (e.g. expectations of health), emotions (e.g. fear of treatment), and behaviours (e.g. smoking, diet, exercise) (Ogden, 2004). In this context, the patients' emotions are most pertinent and it is when there are positive emotions associated with treatment that it is encouraged. In this study, it is seen how the participants' positive emotions towards their health care providers are directly linked to positive feelings towards their health care settings, and their treatment plans.

4.2 Negative Experiences

Three out of the eight participants expressed an indication that they had had or witnessed a negative experience at their own health care setting. The most prevalent theme that came out of this was that they had an experience of lack of resources at the clinic/hospital they attended. Their negative experience was usually centred on one doctor who could not do their job properly. While these experiences seemed to be related to a high doctor/patient ratio, it is significant because it contributes to a negative experience at the health care setting.

One participant relayed information about a doctor himself having a negative reputation for his treatment of patients, however she did not experience this herself; she had only heard this from acquaintances. Participant B “ didn't find the doctor who was not okay with [her] but some other people in the hospital I can hear some other people they say ooh this doctor.....

This doctor is not okay and the one you see they talk everything negative things about him or her but for me ja I don't see any problem”.

Participant H reported that she witnessed a nurse/doctor at a hospital not giving the proper attention to the patients that were more ill. She was “feeling ashamed for the people who is very ill [as] they don't take care of them”. She stated that she did not receive this kind of inattentive treatment as she herself was not so sick:

“Very sick. They can't even walk. They must hire the car to bring them. He can't even sit. There's no stretcher there. There's no wheelchair to take her from the car to the wheelchair. He must stand there in the line. They don't check that this one is very ill let's take her and check her fast. No, you must wait. Maybe you came you are number 36 you must remain there for the whole day. It's not nice”.

This particular participant's reports allude to the fact that the patients who are more ill seem to be getting worse treatment, in this case less attention, than the patients who are relatively healthy. It is difficult to measure the weight of this negative treatment however it is possible that it relates to the stigma of the life threatening status of HIV and AIDS.

As Carlisle (2001) stated, the perception of the virus is impacted by the fact that there is no cure. The fear that is provoked by diseases that ultimately result in death can lead to unreasonable and irrational behavioural responses (Carlisle, 2001 as cited in Mason et al, 2001). Following on the account from participant H, one could postulate that the patients with HIV and AIDS who are more ill and display more symptoms of the disease are seen as being closer to death than the ones who are living healthily with HIV and AIDS. In this case the patients who are more ill might receive ruder treatment as it sparks the irrational fear that is felt when confronted with a life threatening disease. This fear may then be translated into rude behaviour.

The other part of participant H's account relates to the lack of resources that are available in hospitals and clinics. This comprises the subcategory of this theme.

4.2.1 Lack of resources

Two of the eight participants relayed information about the resources that are available to them at the clinics and hospitals that they frequent. It was picked up that what the participants believed to contribute to their experiences at their health care setting was the

availability of the doctor, his time, and the resources at the hospital. These findings do not directly relate to the purposes of this study in that they are not associated with experiences in terms of attitude and perceptions of the doctors and/or nurses. However it was felt important to include in the discussion as it does affect the patients' experience at the clinic.

As was seen above, participant H speaks about the fact that at the hospital she attended there was "no stretcher there...there's no wheelchair to take her from the car...[patients] must stand there in the line...it's not nice". This shows how the fact that the hospital not having sufficient resources affects the patients experiences there.

Participant H also speaks about the lack of doctors at the clinic she attended. She says that "It was fine but it's not good for one doctor". She reports that "he came once a year for a lot of patient". This was "not enough for her because when we are more than 60" and "when you come where you number maybe 45 already he is so tired he doesn't do anything ...".

This does not explain whether the patient felt a negative experience due to her status or not, but does give some insight into the type of treatment she is receiving at the clinic. She does not relate it as having to do with her status, but believes that she deserves better treatment than that and justifiably feels that one doctor is not enough for sixty patients. This contributes negatively to her experience at the clinic as she seems to feel frustrated with the situation.

This was also relayed by Participant E who has also had a negative experience with a doctor. This participant feels that the doctor "is not good" and that she "don't check us". She states that the doctor "just asks you what's the problem....and then she says you are okay, you look fine" without actually examining the patient. The doctor "is always on the phone" and "does not have time". The participant is also frustrated as she has experienced wanting to see the doctor and gets told "no the doctor is not coming today... today there's no doctor".

This again shows the lack of resources, in this case not having enough doctors at the clinic to be available at all times rather than on one particular day. Furthermore this participant feels that the doctor that is available is not sufficient and she does not feel that she gets proper treatment.

Feeling that one is getting the proper care at a health care setting is part of the experience of attending health care settings. Although the examples outlined above do not seem to be related to the participant's HIV and AIDS status, it is clear that they do not feel as if they are

getting the proper care. Soto, Bell and Pillen (2004) found that the biological, social and psychological needs of patients should be tackled as one element rather than being looked at individual aspects of a patient's care. This means that all three elements of care are interrelated.

They state that behavioural interventions which are combined with medical care are more responsive to patient needs and play a significant role in promoting treatment adherence and improving health outcomes (Soto, Bell & Pillen, 2004). While this study as focused on the behavioural and social aspect of improving health outcomes, these accounts from the participants show that the medical aspect holds as much weight and that receiving the bare minimum of medical care can have as much of an impact on their personal experiences at the clinic as the emotional treatment they receive. It is important to note that although these participants had complaints about their experiences in terms of treatment, availabilities of doctors and the resources, they did not believe that this had anything to do with their status. Furthermore, these experiences did not stop them from attending their health care settings or taking their medicine.

4.3 Personal Factors

This theme emerged in six of the eight participants. There were three different subcategories within this theme, namely Religion, Own Motivations, and the Passage of time. Whilst it was considered that these did not directly relate to the research question, these factors emerged as important aspects of the participants' self care, which were closely linked to their motivation to continue visiting their health care settings and adhering to their medication. As such, they were believed to be significant to the study and valuable to include in this chapter. Participants reported how their own cognitions and attitudes towards their HIV status impacted on their motivation to continue going for checkups and taking their medication so that they could continue to live a healthy life.

4.3.1 Religion

Religion emerged for two of the participants as being a major force in the way in which they dealt with their status. They reported that at first they did feel a level of fear in terms of their future as well as what was going to happen to them. There is a sense that by turning to religion and praying to god enables them to live with a sense of purpose.

“Since I found out that I’m HIV positive no it was bad and I told myself, why me, why I’m HIV positive but you know one thing I have made I only pray to God and then I told God you know what God everyday with you there is nothing that I – there is nothing that can like I can – I won’t die without you. You are the only one who knows why I have HIV positive or I’m negative you know. Ja, so I pray to God you know you must help me through everything, ja. Through difficulties you know everything that you are going through ja with AIDS”.

Participant A

She then went on to state that she feels like this had “helped a lot”. Participant B spoke about how she was at one stage very sick and thought she was going to die in hospital, and still didn’t feel scared. She says that she said “to my God whatever happens in this hospital I will take it”. She states that she didn’t feel scared just because she was sick. Both participants explain how even though at first there was a level of fear, it did not stop them from visiting the hospital. They turned to God to help them survive through their fear and continued to go to the hospital to get their medication.

It could be postulated that without this source of support, these participants may have felt hopeless and powerless which could have resulted in a sense of desperation where they did not hold a belief in the worth of continuous hospital visits and medication adherence. This therefore emerges as another source of support, just as important as the support they experience at the actual health care setting. As was mentioned above, being involved in a supportive relationship is an important indicator of continuous medication adherence (Nachega et al, 2006). It was suggested above that the supportive relationship could exist between patient and doctor and/or nurse. In this case it suggested that a patient’s relationship with their religion and their God could also function as a supportive relationship as it allows the patient to feel less fearful and therefore more in control.

These findings also support previous research that has been conducted on the relationship between spirituality and coping mechanisms for people living with HIV and AIDS. It has been found that people with HIV and AIDS who have more positive religious coping strategies, such as a secure relationship with God, a belief in life’s larger meaning, and a sense of spiritual connectedness with others (Pargament, Smith, Koenig & Perez, 1998), show higher levels of well being over time (Trevino et al, 2010). Expanding on this, Russell et al. (2003) found that belief in the importance of a spiritual life, reading the Bible, having faith in God and putting life in God’s hands greatly affected medication taking of people

living with HIV and AIDS. This previous research, together with the current findings, suggest that a person's spiritual beliefs have an influence on the manner in which they deal with their health experiences. Essentially, the premise is that it is their spiritual faith that helps them to cope with their illness, which in turn enables them to continue visiting health care settings and taking their medication, regardless of their experiences at the health care settings. The spiritual faith therefore acts as a facilitating factor in its own right.

4.3.2 Re-evaluation of Self in the Face of an HIV and AIDS Diagnosis

This is the second of the three subcategories to emerge in this theme. Certain insights into the participants' own attitudes and beliefs about their status and health seeking behaviour materialised from the data. Again, it was thought pertinent to this current study as it shed light on their own involvement in their treatment. Whilst most of the themes and subcategories have looked at external factors, this one takes into account the participant's own feelings and how they use these to process their situation and in turn their treatment.

Participant A uses a normalising method to deal with her own fears and beliefs. She says that "there are many diseases that they cannot be curable so why can't I cope with this disease". In this way she is "normalising" having HIV and AIDS in terms of it being just like other illnesses that are not curable and therefore should not hold more weight or significance than any other disease. Carlisle (2001) maintains that it is the uncertainty that surrounds the cure for AIDS which continues to have a great impact on the way in which HIV and AIDS psychologically affects those people who are infected and affected. Participant A is realising for herself that this uncertainty does not need to have an influence on her psychological well being as it is just one of many diseases that are incurable. In this way she is negating the discrimination and prejudice that exists around HIV and AIDS by comparing it to other illnesses.

When asked if she was scared that she would be looked at differently at the hospital she frequented because of her HIV status, Participant D responded by saying that she "always told [herself] everybody is sick in this world". She stated that she must accept herself before somebody else can accept her. This is another example of the participant creating her own belief system surrounding her status. By stating that she must accept herself before someone else can accept her, she acknowledges her own role in acceptance. Furthermore, by telling herself that many people in the world are sick, she normalises the disease by realising that it

is not just her that has HIV and AIDS and therefore does not need to view herself as being different.

It has been reported that people living with HIV and AIDS often experience their own self-depreciating beliefs about their illness. They often feel dirty, ashamed and as if they themselves were to blame. These beliefs, added to the discrimination that is often experienced as a result of having HIV and AIDS have a large influence on the psychological well being of people living with the disease (Simbayi et al, 2007). It is therefore clear how important it is that these participants are able to live without these self-depreciating beliefs as it enhances their self esteem. By creating a good self image, without placing blame on themselves, these participants are able to fully embrace their status and the treatment that is necessary to live a healthy life. Furthermore, it is suggested that having a high self esteem leads to a desire to carry on living which in turn would have a direct impact on their medication adherence. In the case of Participant D, her ability to accept herself regardless of other people's perceptions of her leads to a lack of self depreciating beliefs about herself and her status.

These sentiments were shared by Participant G who spoke about her own realisation that anyone can contract HIV and AIDS:

“Because I know HIV you can get wherever even if you care about someone who is HIV you can get HIV and many people got HIV. So if I'm continued with scared I can't teach other people with HIV so I supposed to teach other people about HIV so that they can know especially the young one”

She spoke about the fact that it was this realisation that helped her in overcoming her own fears and anxieties about the disease. In her case, she reported how important it is for her to accept her status so that she can share her knowledge and experiences with other people, especially younger people. In this sense, she is putting herself in a position to support others. The fact that she acknowledges that “HIV you can get wherever” also relates to the stigmatisation that can take place due to the associations that are made between HIV and AIDS and its origins. It is often associated with homosexuality, sex worker and intravenous drug users (Carlisle, 2001 as cited in Mason et al, 2001). In this way, the disease is seen as being a result of behaviour that is generally perceived as being taboo or immoral (Gilman, 1988; Patton, 1990; Sontag, 1988 as cited in Strebel, 1997).

4.3.3 Dealing with the Fear of Stigma

The final subcategory within this theme, this element materialized as an interesting part of the participants' cognitions with regards to their fear about their status. Three of the eight participants related instances about how at first they did experience feelings of fear, but that after some time had passed this fear and anxiety dissipated. This section deals with how they overcame this by themselves.

Studies have shown that patients sometimes feel scared of being seen at HIV clinics. This expectation of stigma took priority over the potential benefits from treatment (Daftary et al, 2007). In this particular study it was found that there were more instances of felt stigma than enacted stigma. Felt stigma alludes to the fear of being discriminated against, whereas enacted stigma is the actual experience of being discriminated against. Felt stigma drives a person to isolate themselves from others due to the anxiety they feel about the chance of being stigmatized (Scambler, 1998 as cited in Daftary et al, 2007).

Participant G shares how her ability to normalise her status helps in alleviating the felt stigma she may otherwise experience. By understanding that the origins of HIV and AIDS are not from behaviours that are considered immoral or deviant she eliminates the feeling of prejudice and discrimination for herself and does not need to fear being seen at a treatment centre and can therefore reap the benefits of visiting health care settings and taking her medication.

Participant A's personal motivation comes through in a different manner. She speaks about how she goes to the hospital and continues to take her medication for herself in order to continue to live:

"I must always continue to take my treatment because if I don't go and take my treatment, I'm going to die and I'm going to die for myself"

In a sense, Participant A is taking ownership of her status and the fact that it is up to her to take her medication in order to live. While she does give acknowledgment to the fact the support she receives at the hospital plays an important role, she maintains that it is her that will suffer if she does not take her treatment and therefore it is up to her to make sure this

happens. It is her motivation to live a healthy life that works as a driving force in her medication adherence.

As was mentioned above, the biopsychosocial model of understanding health incorporates psychological (*psycho*) and the environmental (*social*) factors into the already established biomedical (*bio*) model of health (Ogden, 2004). The cognitive, emotional and behavioural aspects that make up the *psycho* part of the model all play a role here. The way in which these participants' normalise their experiences shows a cognitive understanding of their position and results in intellectualising their status. They rationally understand that living with HIV and AIDS is similar to living with any other incurable disease and therefore realise that in order to live they need to take their medication. This intellectualising leads to them to eliminate the felt stigma that may occur otherwise. Furthermore, this then results in a lack of fear which leads to healthy behaviour. In this way it can be seen how all these aspects of the biopsychosocial model work together in order to promote treatment adherence.

Participant A was diagnosed with HIV three years before the interview took place. As was seen above, she states that the doctors and nurses at the health care setting she attends are supportive and educative about HIV and AIDS and that she has had positive experiences there. However, when asked if she ever felt scared when she first started going to the hospital, she responded by stating that "the first time I was scared you know, and the people, how the people they are going to treat me if I tell them...but then time goes on you know and I realised that there is nothing that I can be afraid of what I'm living with you know".

At the time of interview, Participant B had been living with HIV and AIDS for ten years. She too stated that she "was not scared" of being treated badly at the hospital and that the doctor is "nice to me". When asked if she felt fearful at the beginning of her treatment process, she responded with "Ja, the last time it was – I had the stress, but now, uhuh". Participant G had been diagnosed four years previously. She stated that "at the first time I was worried but when I was talking with some other people at the hospital so now I'm not coming scared".

All three of these participants speak of how they appreciate the support and encouragement they receive in various forms from the different health care settings they frequent. However, as was noted, they have all been living with this illness for a considerable amount of time. All of the participants were asked how they felt at the beginning of their treatment process. These three ladies responded with a sense of fear and anxiety for what they were going to

encounter, whether it be the attitude of the doctors or the actual treatment they would receive. This again falls into the cognitive aspect of the *psycho* part of the biopsychosocial model. Their expectations of treatment were affecting their emotions. However, as time went on these anxieties disappeared. Hence, it can be suggested that it was the fear of the unknown that was impacting their feelings towards their health care settings. Once they realized what the procedure would be, as well as encountering friendly, supportive health care workers, their fear went away enabling them to continue visiting the health care setting and taking their medication.

CHAPTER FIVE:

CONCLUSION

5.1 Limitations of Study

One of the largest limitations of the current study was the language barrier that existed between the researcher and the participants. Whilst the researcher made every effort to ensure that the participants involved in the study were English speaking, gaining assurance from the participants themselves that they could understand and converse in English, it proved to be more difficult when the interviews actually took place. There were many misunderstandings during the interviews and at times the researcher felt the participants were struggling to understand the questions. This resulted in the researcher having to change the wording of many of the questions in order to simplify it. It is possible that in doing this much of the meaning of the question was lost. Furthermore, it is possible that by changing the language of the questions the researcher could have unwillingly asked leading questions.

Another limitation that was noted is in relation to the sample group. The fact the participants were found by approaching an HIV and AIDS support group may have had implications on their answers. By virtue of the fact that these participants all attend a support group, it is possible to suggest that they have a vested interest in their status and talking about their situations. It was told to the researcher that these participants are all very proud of their status and believe in the power of talking and sharing. This therefore could result in them all holding similar attitudes and beliefs about their experiences which could sway the results. Due to the fact that this was a select group of people living with HIV and AIDS, it could explain why they had very similar attitudes towards experiences and adherence. Furthermore, it is only women who attend this support group. This meant that no men were available to interview. This leads to a reduction in variability in the sample.

Although one of sample criteria was that participants had to have been living with HIV and AIDS for longer than three months, all of the participants interviewed had been diagnosed over three years previous to the time of interviewing. This had implications on their answers with regards to their experiences. Although some of them could remember how it was at the beginning of their treatment process, because they had all been living with the disease for so many years there was almost a sense that they had made peace with their situation.

Furthermore, it was difficult for them to remember what their experiences were when they first started attending health care settings for their treatment.

Most of the participants had also attended only one health care setting for their HIV and AIDS related treatment. This meant that certain questions relating to their health seeking behaviour were impossible to answer as this behaviour was only made up of visiting either a hospital or clinic. Furthermore, the participants could obviously not compare their experiences at different health care settings in relation to HIV and AIDS related care. Moreover, certain participants spoke of the fact that they would need to be transferred to a different clinic if they wanted to change, as well as relating information that many of the clinics they attended were ones that were close to them so they didn't need to get transport. This affects their experiences in that it suggests that they do not have much choice regarding their health seeking behaviour.

Another important limitation to mention were the time constraints the researcher was under. It was due to these time restrictions that the additional questionnaires could not be translated and used as supplementary data to the initial interviews. Although it was felt that the interviews yielded enough information to gain a general sense of the participants experiences, it is possible that the extra questionnaires could have shed more light.

5.2 Implications for Further Research

One of the major themes that emerged from the data was the participants' ability to re-evaluate their own beliefs in the face of their diagnosis and the impact this had on their attitudes regarding their HIV status as well as their need to adhere to their medication. It may be beneficial to further explore this area, looking at how people living with HIV and AIDS use personal motivation and whether this is a good predictor of medication adherence. This could be taken further to investigate ways of increasing personal motivation, and what barriers could exist in this field.

Related to personal motivation is the exploration of what was suggested as alternative treatment support relationships. Instead of the common supportive relationship existing between patient and family member, it would perhaps be valuable to examine the significance of alternative relationships existing between the patient and their doctor, as well as between the patient and their religion. Investigating these relationships could shed light on how all these interacting dynamics could affect treatment adherence.

It could also be interesting to look at the experiences of inpatients at hospitals and clinics. All the participants interviewed were living healthy lives with HIV and AIDS. However certain instances gathered from the data alluded to the fact that the very ill people with HIV and AIDS who are admitted to hospital received different treatment from the doctors and nurses. It is suggested that a similar study be conducted in order to explore whether inpatients have positive or negative experiences at their health care settings. In this way, comparisons could be drawn between people living with HIV and AIDS who are living healthy lives and the more ill people living with the disease who are admitted to health care settings for an extended amount of time. The data suggests that these people receive worse treatment because they are more ill, and perhaps it would be interesting to investigate whether the visibility of symptoms plays a role in the treatment of people living with HIV and AIDS.

Most of the instances that emerged in relation to negative experiences at health care settings for the participants were associated with lack of resources, time and doctor availability. Participants all spoke from an HIV and AIDS perspective. It is suggested that to explore the experiences of other patients attending health care settings for different illnesses could be useful in ascertaining whether these negative experiences are felt on a global level or only by people living with HIV and AIDS. It can be hypothesised that what is construed as rude treatment from doctors or nurses may be a result of the poor working conditions and not because of the fact that their patients are living with HIV and AIDS. This then leads to a further implication for study, looking at doctor and nurse experiences in hospitals and clinics and how their working conditions affect their behaviour towards their patients.

5.3 Concluding Remarks

The study set out to investigate the experiences of people living with HIV and AIDS at their health care settings and whether they affect their health seeking behaviour. The aim was to explore whether people living with HIV and AIDS are experiencing positive or negative treatment at the health care settings they frequent. Secondly, it examined what kind of effect these positive or negative experiences had on their health seeking behaviour, specifically their willingness to keep visiting their clinics/hospitals and their motivation to continue taking their medication. The methods used were semi-structured interviews which took place at the SACTWU worker health programme. The sample consisted of eight women who are

currently living with HIV and AIDS. The interviews were transcribed and analysed and produced the following results:

Participants reported both positive and negative experiences at their respective health care settings. The positive experiences were related to the counselling and education services that were received by the participants, as well as the supportive relationship that existed between doctors, nurses and patients. It was felt that the counselling and educational services added to their experiences at their health care settings in the sense that they helped in reducing feelings of despondency, fears of discrimination, and added to their feelings of comfort in being able to ask questions about their state of health.

Doctor and Nurse Empathy, Patience and Personal Interest emerged as the most meaningful category in the positive experiences theme. Participants were highly complimentary in their accounts of the treatment they receive from their doctors and nurses. They reported on how their encouragement, understanding, patience, personal interest and nice treatment all contributed towards positive views towards their health care settings and what they experience when they attend their appointments. They also stated that these are all contributing factors towards their motivation to keep attending and assists in adhering to their medication.

Negative experiences were reported in terms of lack of resources that were experienced at certain clinics and hospitals. Many of the participants reported a feeling that the availability of doctors and supplies was insufficient and played a role in negative experiences being felt at their health care settings. There were also reports of patients who are more ill receiving worse treatment than the patients who are healthy. While these negative experiences are not directly related to the research questions, they were deemed significant to the study in that they added to feelings of discontent with experiences at health care settings.

Finally, Personal Factors were found to be important aspects of the participants' self care, which was closely linked to their motivation to continue visiting their health care settings. These factors were divided into *religion*, which emerged as an important motivating factor, *re-evaluation of self in the face of an HIV and AIDS diagnosis* as well as *dealing with the fear of stigma*. These two subcategories explored how the participants were able to re-evaluate their own beliefs and attitudes regarding their status and how this enabled them to make peace with their illness. This then contributed to personal motivations to continue taking their medicine in order to stay healthy.

The findings explained above suggest that, for people living with HIV and AIDS, medication adherence and continued visits to health care settings are greatly influenced by positive experiences at these health care settings. While negative experiences do affect the level of comfort at the health care settings, the findings suggest that these are not often experienced and if they are, personal factors were found to be more significant in contributing to visits to health care settings and medication adherence.

CHAPTER SIX:

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Appendix A



Letter of Permission to the Head of Institution (Qualitative/Interview Based Research)

School of Human and Community Development
Private Bag 3, Wits 2050, Johannesburg South Africa
Tel: (011) 717 4502 Fax: (011) 717 4559

Dear Sir/Madam

My name is Claudia Abelheim and I am conducting research for the purposes of obtaining a Masters degree in Educational Psychology at the University of the Witwatersrand. My area of focus is whether people living with HIV and AIDS have any positive and negative experiences within the health care setting and whether this affects health seeking behaviour for people that are living with HIV and AIDS. I will need to interview people that are living with HIV and AIDS and I would like to invite patients that attend the SACTWU Worker Health Program to participate in this study.

Participation will involve interviewing patients at a time and place that is convenient for them. The interview will last for approximately 40 minutes. With the participant's permission this interview will be recorded in order to make sure that I can capture the right information. Participation is entirely voluntary, and no person will be advantaged or disadvantaged in any way for choosing to participate or not participate in the study. Participants may refuse to answer any questions they do not feel comfortable answering and may choose to withdraw from this study at any point.

It will not be possible to keep the interviews anonymous, as they will be done face to face, and it is possible that an interpreter might be used. However, once the interview is finished all of the responses will be kept confidential, and no identifying information will be included in the research report. The interview material (tapes and transcripts) will not be seen or heard by any person in this organisation at any time, and will only be processed by myself.

However, certain quotes from the interviews may be used in the final report, but once again these quotes will be kept confidential. No names will be given when using quotes in the final report. The material will be kept in a locked cupboard that only myself and my supervisor will have access to. Once the research report has been passed, all material will be destroyed.

Once the results have been obtained, and the final report has been written up, the report will be seen by members of the University of the Witwatersrand. The report will also be made available to you should you desire it.

Should you consent to the study being carried out at SACTWU Worker Health Program, I will then personally approach staff members to arrange a suitable time to approach prospective participants, where they will then be invited to participate in the study.

Should you have any queries, please do not hesitate to contact myself or my supervisor.

Kind regards
cc Head of Department of Medicine
cc Head of SACTWU WORKER HEALTH PROGRAM

Claudia Abelheim

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Supervisor: Mambwe Kasese-Hara

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Appendix B



Letter of Permission

25 January 2010

Ms Claudia Abelheim
School of Human and Community Development
University of the Witwatersrand

Dear Ms Abelheim

“People living with HIV and AIDS: An exploration of their positive and negative experiences in Health-Care Settings and whether it affects their Health-Seeking Behaviour”

This is to confirm that permission is given to Ms Claudia Abelheim to conduct research here at *SACTWU Worker Health Program* in the form of interviews.

Kind regards,

Lindiwe Dambuza
Managing Sister
SACTWU Worker Health Program

Appendix C



Subject Information Sheet (Qualitative/Interview Based Research)

School of Human and Community Development
Private Bag 3, Wits 2050, Johannesburg South Africa
Tel: (011) 717 4502 Fax: (011) 717 4559

Hello,

My name is Claudia Abelheim and I am doing research so that I can receive a Masters degree in Educational Psychology at the University of the Witwatersrand. I am looking at whether people living with HIV and AIDS have any positive and negative experiences at the health care settings they go to and what makes up health seeking behaviour for people that are living with HIV and AIDS. I will need to interview people that are living with HIV and AIDS and I would like to invite you to take part in my study. I will come to the clinic to meet you and explain the study to you, and the managers of the clinic will not be involved in this process.

If you would like to take part, you will be interviewed by me at a time and place that is easiest for you to get to. The interview will last for about 40-60 minutes. With your permission this interview will be recorded so that I can make sure that I can gather the right information. Taking part in this is entirely voluntary and up to you, and no person will receive any benefits or be disadvantaged in any way for choosing to participate or not to participate in the study. You may refuse to answer any questions you do not feel comfortable answering and you may choose to pull out from this study at any point without any negative consequences.

Once the interview is finished all of your answers will be kept confidential and private, and no information that could identify you would be included in the research report. The interview material (tapes and transcripts) will not be seen or heard by any person besides for myself and my supervisor. However, certain quotes from the interviews may need to be used

in the final report, but no names or other identifying information will be used. The material will be kept in a locked cupboard that only myself and my supervisor will have access to. Once the research report has been passed, all material will be destroyed.

Once I have the results, and the final report has been written up, the report will be seen by members of the University of the Witwatersrand. The report may also be given to the managers of the SACTWU Worker Health Program. If you would like a summary of the research, this can be arranged.

If, after the interview, you are at all troubled or upset by what was spoken about during the interview, free counselling will be provided and arranged at the Emthonjeni Centre at the University of the Witwatersrand (011 717-4513). This is near to the clinic and I will arrange transport for you and will pay for it if you need counselling.

If you choose to participate in this study please fill in your details on the attached consent form. I will return to collect the forms within the next three weeks. Alternatively I can be contacted by telephone at (011) 447 6975/ 082 651 1006 or by email at cabelheim@gmail.com. If you have any questions, please do not hesitate to contact me or my supervisor, Mambwe Kasese-Hara, at (011) 717 4552/3 or by email at Mambwe.Kasese-Hara@wits.ac.za.

Once you have read this information sheet and understood everything in it, please take care with it, as the information on this sheet could disclose your HIV status if it is seen by anyone else.

Kind regards

Claudia Abelheim
082 651 1006

Anisa Keshav
Human Research Ethics Committee Secretary (HREC)
(011) 717 1234

Lindiwe Dambuza
Managing Sister
SACTWU Worker Health Program
(011)

Supervisor: Mambwe Kasese-Hara
011 717 4552/3

Peter Cleaton-Jones
HREC Chairman
(011) 717 2301

Appendix D



Consent Form (Interview)

I _____ agree/disagree to being interviewed by Claudia Abelheim for her study on positive and negative experiences at health care settings, Health Seeking Behaviour and HIV and AIDS. I understand that:

- Taking part in this interview is voluntary and is my own decision.
- That I do not have to answer any questions I would prefer not to.
- I may pull out from the study at any time.
- Direct quotes or sayings may be used in the final report.
- There will not be any personal benefits or drawbacks for choosing to be involved in the study
- No information that may name me will be included in the research report, and my responses will remain confidential and private.
- An interpreter may be used if the need arises.

Signed _____

Anisa Keshav
Human Research Ethics Committee Secretary (HREC)
(011) 717 1234

Peter Cleaton-Jones
HREC Chairman
(011) 717 2301

Appendix E



Consent Form (Recording)

I _____ agree/disagree to my interview with Claudia Abelheim for her study on positive and negative experiences at health care settings, Health Seeking Behaviour and HIV/AIDS being tape-recorded. I understand that:

- The tapes and transcripts will not be seen or heard by any person in this organisation at any time, and will only be worked with by the researcher and her supervisor.
- All tapes will be kept in a locked cupboard that only the researcher and her supervisor will be able to get into, while the study is going on.
- All tape recordings will be destroyed after the research is finished.
- No information that could name me will be used in the transcripts or the research report.

Signed _____

Anisa Keshav
Human Research Ethics Committee Secretary (HREC)
(011) 717 1234

Peter Cleaton-Jones
HREC Chairman
(011) 717 2301

Appendix F

Interview Schedule:

1. Biographical Information:

- Age
- Gender
- Time since diagnosis
- Where do you normally go for care?
- Do you go anywhere else?
- Are those the only places you go?

2. Experiences in general at health care settings

- How do you feel you are treated at the health care settings you visit?
- Can you elaborate or tell me more about it?
- If you visit more than one setting, are there differences between these settings in your experiences?
- Can you tell me more about this?
- Do these experiences affect which setting you choose to visit?
- Can you elaborate on this?

3. Negative Experiences

- Have you ever been scared that you will be treated differently in health care settings?
- Can you tell me more about this?
- If you have been concerned about this, has this fear ever stopped or influenced your attending any of the health care settings?
- Have you ever had any experiences of people seeing you as different or treating you differently at any health care settings?
- Can you tell me more about this?
- Has this happened at all the health care settings?
- Can you say more about this?

- If you have had any of these experiences, have they ever stopped or influenced your attending any of the health care settings?

4. Positive Experiences

- Have you ever had any positive experiences at the health care settings you visit?
- Can you explain why these experiences felt positive to you?
- Did these experiences encourage you to seek further help or treatment?
- What about these experiences made you want to seek further treatment?

Appendix G: Additional Questionnaire

1. What do you enjoy about visiting your clinic?
2. What don't you enjoy about visiting your clinic?
3. Do you experience a feeling of wellbeing when you visit?
4. What creates this feeling for you?
5. Do you ever feel anxious or afraid to visit your clinic?
6. What contributes to these feelings?
7. Are there any factors about the clinic or health care setting you visit that encourage you to continue going for check ups?
8. Are there any factors about the clinic or health care setting you visit that encourage you to continue taking your medication?
9. Are there any factors about the clinic or health care setting you visit that discourage you from going for check ups?
10. Are there any factors about the clinic or health care setting you visit that discourage you from taking your medication?