BARRIERS TO ORAL HEALTH CARE AMONG PEOPLE LIVING WITH HIV IN KWAZULU NATAL AND THE WESTERN CAPE

by

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Abstract

Introduction

HIV/AIDS is a major problem in South Africa with more than 25 percent of the adult population infected with HIV. Oral lesions and various opportunistic infections characterize the progression of HIV making it imperative for people living with HIV to have access to good quality oral care. There is a need to examine accessibility and use of dental services in South Africans living with HIV as very little research in this regard, has been undertaken.

Aim

To investigate the barriers to oral health care for people living with HIV in the KZN and the WC.

Research Design and Methodology

A cross-sectional study utilising a self-administered questionnaire and semi-structured interviews has been employed. Participants were people living with HIV older than 18 years attending HIV clinics located throughout Kwa-Zulu Natal and WC. Binary logistic regression was performed to determine the variables associated with not obtaining care.

Results and Discussion

The sample (n=435) comprised mainly of black females in the age group 20-29 years. There were statistically significant differences in terms of socio-demographic factors between the two provincial cohorts. Of the total number of participants, 347 (79.8%) had an oral health problem and 83% (n=288) received care. Of those that received care, more than half of the participants (57.6%) reported that the staff were aware of their HIV status. Almost a third of the participants who received care reported a negative experience. Of those that did not receive care, there were disparate reasons between the two provincial cohorts. In KZN, the reasons for not receiving care related to the service being unavailable, too far away or lack of money to pay for transport and for the service, while in WC, participants had no money to pay for transport and for the service, but were mostly afraid of discrimination, stigmatisation and lack of confidentiality.

If the participant lived in a metropolitan area, they were 3.647 times more likely to receive care than those in a non-metropolitan area (p <0.01); if the participant had not moved recently into the area where the participant was currently residing, the participant was 0.324 times less likely to receive care compared to someone who had moved recently (p = 0.002); if the participant lived 1-5km from the clinic, the participant was 3.371 times more like to receive care (p = 0.015); if the participant had been working part-time for the past year, the participant was 0.107 times less likely to receive care (p = 0.011) and if the participant earned R5000 or less, the participant was 0.106 times less likely to receive care (p = 0.048).

Conclusion

This study provides evidence that people living with HIV still have unmet needs and experience barriers to oral health care. The results suggest that certain groups such as women, the unemployed, low income earners and people living with HIV in non-metropolitan regions have difficulty accessing oral health care. Discrimination and stigmatisation also pose barriers to accessing oral health care. Specific strategies need to be incorporated in the broader oral health care strategy to improve the status quo.

Recommendations

It is important for the national and provincial Departments of Health to acknowledge the barriers to oral health care experienced by people living with HIV/AIDS and to fine tune policy, educate staff and monitor processes with regards to the management of HIV/AIDS to ensure that staff are competent to carry out their duties while respecting the rights and dignity of those living with HIV and avoid discrimination and stigmatisation. Those that have an unmet need for care may benefit from social and financial support.

Keywords: HIV, oral health care, barriers

Declaration

I, the undersigned, hereby declare that the work contained in this dissertation is my original work and that it has not been previously in its entirety or in part submitted at any university for a degree.

…………………………………… …………………………

Mervyn Sydney Turton Date

Dedication

To my parents, Kenneth and Afra Turton,
and my brothers,
Clive, Lionel and Russell,
for their unfailing, steadfast support.

For my son, Bryden and daughter, Elizabeth.

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List of Abbreviations

AIDS	Acquired immunodeficiency syndrome
HAART	Highly active antiretroviral therapy
CHC	Community Health Centre
CI	Confidence Interval
DOH	Department of Health
HIV	Human immunodeficiency virus
KZN	Kwazulu Natal
NGO	Non-governmental organisation
SANAC	South African National AIDS Council
StdDev	Standard Deviation
STI	Sexually transmitted infection
VCT	Voluntary counselling and testing (for HIV/AIDS)
WC	WC

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CHAPTER 1: INTRODUCTION

Sub-Saharan Africa remains the worse affected region of the HIV/AIDS pandemic. Although just over 10% of the world's population live in this region, more than two out of three (68%) adults and nearly 90% of children infected with HIV live here. More than three in four (76%) of global deaths due to an AIDS-related illnesses in 2007, occurred in Sub-Saharan Africa. This proportion is stark evidence of the unmet need for antiretroviral treatment in the region. Southern Africa alone acocunted for almost one third (35%) of all new HIV infections and AIDS deaths globally in 2007. Sixty seven percent of all people living with HIV live in this subregion (UNAIDS, 2008).

In 2005 about 5.54 million people were estimated to be living with HIV in South Africa, with 18.8% of the adult population (15-49 years) and about 12% of the general population affected. Women are disproportionately affected; accounting forapproximately 55% of HIV-positive people. Women in the age group 25-29 are the worst affected with prevalence rates of up to 40%. For men, the peak is reached at older ages, with an estimated 10% prevalence among men older than 50 years. HIV prevalence among younger women (<20 years) seems to be stabilizing, at about 16% for the past three years (SANAC, 2007).

The clinical presentation and natural history of the disease is characterized by oral lesions (Greenspan, 1997; Begg et al, 1997) and various oral opportunistic infections (Arendorf et al, 1998; Marcenes et al, 1998). These lesions and infections are treatable and in most instances require dental intervention (Arendorf et al, 1998), thus the accessibility to good quality oral care to people living with HIV cannot be over-emphasized.

Various factors are considered to affect the accessibility and utilisation of dental services in the general population (Lalloo et al, 2004). They include factors related to accessibility, equitable service delivery, affordability, accountability and acceptability of the service. These factors are even more pertinent for the people living with HIV who have increased need for dental care (Capilouto, 1991). The diagnosis and management of HIV associated oral lesions and infection control issues have been more researched than the dental needs of HIV infected patients (Phelan, 1997). Many studies have reported that people living with HIV have unmet needs for dental care (Shapiro et al, 1999; Robinson et al, 1993; Patton et al, 2003). Little if any research has been done on the accessibility and utilisation of dental care in South African people living with HIV.

Barriers to health care are obstacles within the health care system that prevent vulnerable populations from receiving health care they need, or predisposes them to get inferior health care compared to other patient populations (AMSA, 2008). Barriers to care lead to disturbing racial, ethnic and geographic disparities in health status and clinical outcomes. Any factor or combination shown in Table 1 constitutes a barrier to care.

Table 1: List of barriers grouped by theme

Geographic	Rural and inner-city health professional shortages
Cultural	Patient health beliefs and behaviours, practitioner beliefs and behaviours
Socio-economic	Lack of insurance, inability to pay for service, poor education
Organisational	Lack of language interpreters or facilities (e.g. wheelchairs), problems with accessibility, long waiting times

Barriers to oral health care for people living with HIV have been identified in studies in other countries (Greene et. al, 1997; Heslin et. al, 2001; Harrison, 2003) but no studies have been carried out in South Africa as determined by a Medline search and a hand search of the literature. It was anticipated that by ascertaining the nature and extent of unmet needs and barriers to dental care for people living with HIV, measures could be put in place to remove or at least reduce the barriers to care and improve the quality of life for people living with HIV/AIDS in South African communities.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

HIV/AIDS gradually and progressively destroys the immune system and it manifests as general and oral infections as well as neoplasms (Begg et al, 1997). The health of HIV infected persons can be severely compromised by untreated oral infections. This could lead to worsening oral health, such as in the case of periodontal disease in an immuno-compromised patient, which could lead to life-threatening infections like infective endocarditis (Ndiaye et al, 1997; Dobalian et al, 2003). Inadequate or no treatment of oral disease can interfere with talking, chewing and swallowing, causing weight loss and malnutrition that can be exacerbated in HIV infected individuals and lead to dire consequences (Dobalian et al, 2003; Arendorf et al, 1998).

2.2 Oral lesions in HIV/AIDS

The importance and relevance of oral lesions in HIV infection have been documented in several studies (Arendorf et al, 1999, Dobalian et al, 2003, Shetty, 2004). Oral lesions are important in HIV infection as they may be:

- predictive of progression of the disease (Laskaris, 1996; Naidoo and Chikte, 1999)
- useful in staging and classification schemes (Begg et al, 1997)
- early clinical features of the disease (Arendorf et al, 1998)
- the initial presenting sign of HIV infection (Arendorf, 1998)
- useful as progress indicators in HIV/AIDS therapy and vaccine trails and in anti-HIV and anti–opportunistic infection therapy (Naidoo and Chikte, 1999).

Oral diseases in HIV infected people are indicative of poor immune function and it is essential for these individuals to have access to regular dental care to ensure they have an opportunity to enjoy the best quality of life (Shetty, 2004; Dobalian et al, 2003).

The important oral lesion markers in the clinical spectrum of HIV infection are oral candidiasis and aphthous ulceration, indicating acute sero-conversion illness (Patton et al, 1999). Oral candidiasis, oral hairy leukoplakia, Kaposi sarcoma and necrotising ulcerative gingivitis may suggest HIV infection in undiagnosed individuals (Begg et al, 1997). Oral candidiasis and oral hairy leukoplakia indicate clinical disease progression and predicts development of AIDS in individuals who are in the advancing stages of HIV/AIDS infection (Naidoo and Chikte, 1999; Laskaris, 1996; Badri et al, 2001). The common oral conditions that occur in HIV infected people can be inspected or palpated during an oral examination and these oral manifestations play a role in the diagnosis and staging of HIV infection (Frezzini et al, 2005; Begg et al, 1997). Oral lesions are commonly used as entry criteria or endpoints in clinical trials of antiretroviral drugs (HRSA HIV/AIDS Bureau, 2001).

2.3 Oral lesions as indicators of HIV infection

According to numerous authors, oral lesions such as oral candidiasis, oral hairy leukoplakia, Kaposi's sarcoma and oral ulcers are more common in HIV infected patients and these lesions are widely regarded as suggestive of HIV infection though this must be viewed with caution in populations where the prevalence of HIV is low (Phelan, 1997; Greenspan, 1997; Arendorf et al, 1998). Robinson et al (1998) reported that in low prevalence areas, the presence of oral mucosal lesions alone is a poor predictor of HIV infection. It has been suggested that to increase the positive predictor value (PPV), the presence of oral mucosal lesions must be combined with a social history to identify risk factors for HIV infection (Naidoo and Chikte, 1999).

2.4 Oral lesions as early clinical features of HIV disease

Lifson et al (1994) showed in three groups with well defined dates of sero-conversion, that oral candidiasis and oral hairy leukoplakia develop at the following rates respectively: 10% within 1 year, 30% within three years and 50% within 5 years. Oral examination is quick and inexpensive and may have a place especially in screening populations at greater risk of HIV, particularly those attending genito-urinary medicine clinics (Naidoo and Chikte, 1999); however, if health care workers are to screen for oral manifestations of HIV, they will need training to identify the lesions (Naidoo and Chikte, 1999).

2.5 Oral lesions in HIV staging and classification schemes

HIV staging and classification systems have been proposed by WHO (1990), Clearinghouse (1993) and the CDC (Centre for Disease Control, 1993) to describe the full range of HIV–related outcomes including oral lesions in populations of developed countries. Revised HIV staging and classification systems have been suggested by Lifson et al (1995) and Arendorf et al (1999) for developing countries, particularly those in Sub-Saharan Africa.

Oral lesions have been shown to be associated with increased risk of progression of HIV disease (Begg et al, 1997). Higher prevalence and incidence rates of oral hairy leukoplakia and pseudomembranous candidiasis are found among people living with HIV/AIDS and the presence of these oral lesions correlate with falling CD4 counts and disease progression (Greenspan, 1997). Oral candidiasis, herpes zoster and oral hairy leukoplakia have been used as clinical indices of disease progression in efficiency trails of Zidovudine (Kinloch-De Loes et al, 1995; Greenspan, 1997) and the development of these lesions occurred at a lower incidence than in the control groups (Carpenter et al, 1996; Greenspan, 1997).

2.6 Oral health and its impact on quality of life

Poor oral health impacts on the quality of life of people living with HIV/AIDS. Oral diseases may cause significant oral pain and discomfort that may lead to problems with eating and poor nutritional intake and result in worsening overall health (HRSA HIV/AIDS Bureau, 2002; Yengopal and Naidoo, 2008). It is imperative to incorporate oral health care in the comprehensive management of HIV/AIDS patients (Ssali, 2000). The impact of oral health on quality of life is in relation to factors such as age group and social class background and in some cases it is in relation to housing, medication adherence and access to care and food (Kenagy et al, 2003). In a study investigating the impact of oral health on the quality of life among women living with HIV/AIDS in Kampala, Uganda (Ssali, 2000), the effect of HIV on oral health and activities of daily living showed that women living with HIV had more problems with eating, cleaning teeth and sleeping due to oral health problems compared to a control group who were HIV negative.

As the prevalence of HIV infected people increases and the ineffective management of the existing cases prevail, there will be an increased need for more comprehensive and accessible health services (Mascarenhas and Smith, 2000) with emphasis on oral health care centres that can provide the necessary care to treat oral manifestations in HIV infected people.

2.7 Dental management of oral diseases in HIV/AIDS

A thorough medical history including a comprehensive review of the physiological systems and a list of current medications should be obtained from all patients. HIV patients must be evaluated for susceptibility to infection and bleeding, potential for adverse drug reactions and drug interactions and the possibility of not being able to withstand dental care related stress and trauma caused by HIV related immuno-suppression and systemic manifestations (De Paola et al, 2003). Severely neutropenic patients should be given antibiotic prophylaxis and elective dental procedures are generally not recommended in patients with a neutrophil count of less than 500 cells per mm^3 and a platelet count of less than 50000 cells mm^3. Those presenting with profound neutropenia and thrombocytopenia require urgent care with possible hospitalization (De Paola et al, 2003). The common oral HIV lesions and their management protocols are listed in Appendix 1.

Patients receiving antiretroviral therapy should be carefully monitored for cardiovascular and diabetes-related symptoms and the patient's blood pressure should be recorded at each appointment. Hepatitis B and Hepatitis C virus are commonly associated with HIV infection and are known to cause liver damage, thus HIV patients must be checked for possible drug side effects due to impaired hepatic function. Acetaminophen should be avoided in cases of severe liver damage because of its hepatotoxicity, while aspirin and non-steroidal anti-inflammatory drugs (NSAID) should not be used in patients with bleeding disorders as they decrease coagulation (De Paola et al, 2003).

2.8 Dental care experiences of people living with AIDS

Many studies have documented the dental care experiences of people living with HIV/AIDS (Jacobson et al, 1989; Robinson and Croucher, 1993; Terry et al, 1994). One of the earliest studies by Jacobson et al (1989) investigated the dental care experiences of HIV infected men in Chicago. They found that many people living with HIV feared being denied access to the dental service and thus visited dentists less often than they did before they learned of their HIV positive status. They also reported that half of the patients who did seek care disclosed their HIV status to the dentist and 97% of those patients were successful in securing care. The explanation put forth in this study for the success participants had in obtaining oral health care was that informed, non-random selection of dentists took place, i.e. the individual had been referred by their physician with whom they had first contact to a dentist known to be willing to treat people living with HIV.

Robinson and Croucher (1993) found that 10% of their study participants admitted visiting a dentist without revealing their HIV status in order to obtain care and 87% of the study group who had disclosed their HIV status to their dentist were refused dental care. This suggested that HIV perceptions of the dental team and participants anxiety about the consequences of revealing their HIV status was a barrier to care for people living with HIV (Robinson and Croucher, 1992; Jacobson et al, 1989, Petrou and Dooley, 1996). Petrou and Dooley (1996) looked at community service needs of people living with HIV in London and found a high level of unmet needs for a wide range of community services, in particular for basic services such as medical and dental care, social work and nursing.

In a survey to ascertain whether or not dental needs of people living with HIV were being met in New Zealand, Terry et al (1994) found that 70% of the participants felt that their needs had not been met. Some participants, however, also reported that their dentist was supportive which was contrary to the findings in the other studies. The reason given for this was that 49% of the participants had changed their dentist; thus, the majority of the participants had either been satisfied with their first dentist or moved to another dentist who was more sympathetic to people living with HIV than the former. Even in this group of participants, 31% did not disclose their HIV status and said that they felt the dentists were taking adequate precautions and that there was no need to volunteer information on their HIV status (Terry et al, 1994).

A study carried out in the San Francisco, United States, by Barnes et al (1996) to determine self-disclosure experiences of people living with HIV seeking dental treatment found that 19 of 20 participants disclosed their HIV status when asked by the dentist. More than two thirds of the participants reported an extremely favourable reaction from the dentist. Established dentist-patient relationships and the network of information shared in the subculture of homosexuals in San Francisco lead to providers and friends referring the participants to dentists who were supportive and sensitive to HIV issues.

2.9 Variations in dental care experienced by people living with HIV/AIDS

Variations in care were found in people living with HIV in the United States especially in minority groups, compared with Whites (Dobalian et al, 2002; Shapiro et al, 1999; Shiboski et al, 1999; Mascarenas and Smith, 2000; Greene et al, 1997; Grace et al, 1994). There were also substandard care reported in the medically uninsured when compared to the medically insured, women compared with men and other risk groups compared with homosexuals (Shapiro et al, 1999). This may reflect underlying discriminatory practices, lower perceived need for dental care, or greater perceived barriers to dental care.

Utilisation of dental care services was significantly more likely among the socio-economically advantaged groups (which occurs more frequently in those categorised as "Whites"), the medically insured, employed with a high education and income and homosexual or bisexual men (Shetty, 2004). Similar trends are observed for medical and dental care in South Africa where health care delivery to poor people dependant on public services, people not previously classified as whites and people living in rural communities is inferior compared to the more affluent counterparts (Lalloo, 2004).

Oral health care workers may not alter the standard of care delivered to a patient solely on the grounds that the patient is HIV positive, unless such variation is deemed to be in the patient's interest (Naidoo and Govan, 2003). According to Naidoo and Govan (2003), there is a perception among some oral health care workers that under exceptional circumstances, the knowledge of the HIV status of a patient may be useful in order to ensure the use of “extended” universal precautionary measures such as special gloves, clothing and face masks and that inexperienced staff should not be allowed to perform surgery on such patients. Health care workers should, however, adopt appropriate universal precautions in all clinical situations rather than rely on knowledge of the HIV status of the patients to ensure that they minimise the risk of infection (Naidoo and Govan, 2003).

2.10 Use of dental services by people living with HIV/AIDS

In the USA, disparities exist in the use of dental services by people living with HIV (Greene et al, 1997; Shapiro et al, 1999). Blacks, Hispanics, people without a high school education and those without dental insurance were all found to be less likely to receive care (Grace et al 1994; Greene et al 1997; Shapiro et al 1999).

Even though the treatment and management of HIV associated diseases has improved since 1990, there is no evidence to show that dental access or utilisation has changed during the same period (Mascarenhas et al, 2000; Heslin et al, 2001). From a national representative sample, Heslin et al (2001) estimated that, of the estimated 230,900 people in treatment for HIV in the United States, 58,000 persons had unmet needs for dental care in the previous month and these needs were twice as prevalent as unmet medical needs (Heslin et al, 2001).

The most common reason for not having received care was not being able to afford treatment (Greene et al, 1997). This was attributed to lack of insurance or medical cover, an inadequate medical cover resulting in cost of treatment not being covered by the medical cover and a lack of affordability (Greene et al, 1997). This is a common trend in most countries including South Africa where homeless, low income earners, unemployed and less educated people have a lack of disposable income and medical cover thus making it difficult for them to access health care (Söderlund and Hansl, 2000). Inadequate use of dental services by people living with HIV was found to be associated with unemployment, perceptions of low income, perceptions of poor health and concerns for problems other than HIV infection (Greene et al, 1997; Shiboski et al, 1999).

2.11 Anderson's behavioral model of health service use

According to Mascarenhas et al (2000), Anderson`s behavioural model states that use of health services is dependant on:

1) Predisposing factors, which is the predisposition of the individual to use health services
2) Enabling factors, which is the person's ability to secure health services
3) Illness level, which is how ill the person is or perceives them to be (Mascarenhas et al, 2000).

Mascarenhas and Smith (2000) used the Anderson's behavioral model of health service use, particularly its individual determinants of utilisation and found that the two predisposing factors that consistently predicted use of dental services were education and race. Similar findings were reported by Greene et al, 1997; Fleishman et al, 1997, Heslin et al, 2001 and Dobalien et al, 2002. Individuals who had tertiary education were more likely to have utilized all the dental services except extractions and the minority groups (Blacks and Hispanics) where less likely than Whites to use all the specific dental services (Mascarenhas and Smith, 2000; Dobalian et al, 2002). Age, gender, marital status and whether an individual worked part-time or full-time were associated with use of dental services (Mascarenhas and Smith, 2000). Older persons living with HIV were found to have more visits to a dental provider (Dobalian, 2003).

Enabling factors were defined to be having medical aid insurance and a place where they could readily access dental care (Heslin et al, 2001; Dobalian et al, 2002) regardless of whether it was public, private or a combination of the two and this was a consistent finding for all types of dental services (Mascarenhas and Smith, 2000). Illness factors such as level of illness and emergency room visits did not predict the use of specific dental services according to Mascarenhas and Smith (2000). However, Greene et al (1997) differed and reported that symptomatic individuals, defined as individuals with two or more oral conditions, were 1.6 times more likely to use dental services compared to those with fewer conditions. Increased use of other health related services such as ambulatory visits and psychological counseling by people living with HIV correlated with an increased use of dental services (Mascarenhas and Smith, 2000).

People living with HIV who utilize these services were generally those who valued the importance of keeping healthy and thus sought services such as oral health care and other health services or were recommended by other health care professionals to seek oral care for their oral health needs (Mascarenhas and Smith, 2000). Similar results were obtained by Greene et al (1997) where 42% of the people living with HIV in their study reported having received dental care after being referred by their primary medical provider.

Dobalian et al (2002) analysed the characteristics of people living with HIV/AIDS who sought dental care and found those who had poor oral health had more visits to a dental provider. Persons in poor physical or mental health (Dobalian et al, 2002), those with a $CD4^+$ cell count of less than 500 cell/Ul (Greene et al, 1997) or those diagnosed with AIDS (Fleishman et al, 1997) were less likely to have obtained dental care. These findings suggest that physical and mental health needs may have a higher priority than oral needs (Dobalian et al, 2002). Discomfort from physical illness creates an urgent demand for treatment whereas lack of motivation from poor mental health may deter individuals from seeking oral care (Fleishman et al, 1997; Heslin et al, 2001; Dobalian et al, 2002). This is in agreement with Coulter et al (2002) who reported that individuals with advanced HIV disease were more likely to need dental care than those in the earlier stage of the disease. This may be explained by the observation that people living with HIV at the advanced stage of HIV/AIDS tend to have more medical and mental health problems making them less likely or able to seek dental care resulting in such individuals not receiving the oral care they need (Coulter et al, 2002).

Women constitute 58% of those infected in Sub-Saharan Africa (UNAIDS, 2004) and many have difficulty to exercise their autonomy, to access educational opportunities and to access health services (UNAIDS, 2004; Anderson et al, 2000) due to economical and social discrimination (UNAIDS, 2004). Furthermore, women are often diagnosed later and have poorer access to health care than men. Women also tend to have higher viral loads and lower CD4 counts (Aberg, 2002). Women have reproductive, social and gender roles that make them vulnerable to problems that do not affect men. These include the health risks and complications of pregnancy and child-bearing, the responsibilities of women as child-rearers and gender discrimination that may culminate in violence toward women. These conditions compound the challenges that women living with HIV/AIDS face (Anderson et al, 2000).

HIV positive women and their families are particularly vulnerable to stigmatization and abandonment by their family friends because of the lower socioeconomic status, cultural traditions and societal beliefs about the role of women (Wang and Celum, 2001). Shetty (2004) showed significantly lower use of dental services in the female patient population at a HIV dental clinic in New Orleans and found that female patients were more likely to seek dental care in the case of an emergency. Female HIV patients were less likely to receive comprehensive dental care (Shetty, 2004).

Shiboski et al (1999) researched dental care access and use among 213 HIV-infected women in the US. They found that 43% of the participants reported that they had not visited a dentist in more than a year and 78% of this group said they had wanted care but failed to obtain care. Dental service use in HIV infected women was found to be associated with high levels of unemployment and having a high frequency of competing concerns that take priority above seeking health care, such as taking care of children and seeking care for HIV-related problems (Grace et al, 1994; Greene et al, 1997; Shiboski et al, 1999).Would this not be similar for HIV negative women of similar social status? There is evidence of this in the literature. I think it is important that you present a balanced view! In the United States of America, non-use of dental services by HIV infected women has been associated with being unemployed, being Black, having self reported poor oral health, and having two or more children (Greene et al, 1997; Shiboski et al, 1999; Zabos and Trinh, 2001). Fear and anxiety are also major determinants of whether women living with HIV will seek oral care or not when they need it. Women who felt anxious or scared about a dental visit were 4 times less likely to seek dental care for a perceived oral problem than those who were not anxious or scared (Shiboski et al, 1999).

2.12 Public perceptions

Utilisation of health care and attitudes towards health are influenced by perception of the risks involved in obtaining the health care or delivering the health care (Grace et al, 1994). In most instances, public perceptions of the risk of infection during treatment in various types of health care settings were found to be based on misinformation and overestimation, and may therefore be inaccurate (Grace et al, 1994).

In their study to ascertain the public knowledge and perceptions about HIV transmission, Grace et al (1994) reported that a more accurate knowledge of HIV transmission was associated with the highest education achieved. The lowest knowledge was among poor and uneducated people who are also most affected by HIV. One may expect the knowledge on the risks of treating people living with HIV to be fairly high among oral health care workers given the level of education that they have attained, yet discrimination against people living with HIV seeking health care is still fairly prevalent among health care workers (Crossley, 2003).

Currently the legislation in most countries, including South Africa, is such that a dentist cannot refuse to treat a patient on the grounds of the patient being HIV positive. Despite this, there is evidence to suggest provider reluctance to treat people living with HIV and other groups that pose a high risk for infection from blood borne pathogens (Crossley, 2003; Shetty, 2004). This provider reluctance severely compromises the HIV infected individual's ability to receive care (Greene et al 1997; Zabos and Trinh, 2001; Shetty, 2004). Reluctance to treat has been linked to considerable gaps in the HIV/AIDS knowledge of providers as reported by Lapidus and Sandler (1997) regarding the dental profession in South Africa.

Dentists who regularly updated their knowledge on HIV/AIDS and hepatitis issues, younger dentists and those experienced in treating HIV-infected patients were found to be more willing to treat people living with HIV (Greene et al, 1997).

2.13 Regular dental care for people living with HIV/AIDS

Regular dental treatment is necessary for people living with HIV to maintain function and a disease-free oral environment because they are predisposed to the various oral manifestations of HIV. Hastreiter and Jiang (2002) investigated whether regular dental visits affected the oral health care provided to people living with HIV and found that neither gender nor age had any significant effect on the regularity of dental care visits. Analysis of the relationship between the distributions of diagnostic and preventative services for HIV infected regular and HIV infected non-regular dental patients, found that the ratio of diagnostic to preventive service was approximately 2:1 for regular patients and 4:1 for non-regular patients (Hastreiter and Jiang, 2002).

Non-regular patients required complex and costly services due to unchecked progression of dental caries and periodontal disease while regular patients received relevant treatment at the right time thus enabling them to retain an intact and functional dentition (Hastreiter and Jiang, 2002).

Coulter et al (2000), one of the research groups of the HIV Cost and Services Utilisation Study (HCSUS) conducted by the Rand Corporation in the United States from 1994 to 2000, found that the characteristic that distinguished people living with HIV who received regular dental care from those who did not, was that those receiving regular care had a regular source of dental care. The perception of unmet need for dental care was associated with age, usual source of dental care, educational level, income employment status, smoking history and dental insurance (Marcus, 2000). These findings are similar to the findings of Greene et al (1997), Fleishman et al (1997), Heslin et al (2001), Dobalian et al (2002) and Shetty (2004). Cost of treatment not covered by insurance, lack of insurance and lack of funds to pay for treatment have been reported as barriers to receiving dental care (Greene et al, 1997; Heslin et al, 2001; Patton et al, 2003; Shetty, 2004).

2.14 Unmet needs for dental care – a look at demographics

Patton et al (2003) investigated the impact of race on perceived oral health status, unmet needs and barriers to dental care in people living with HIV in North Carolina, USA, and found that HIV-infected Blacks were significantly more likely than Whites to be female, older than 37 years old, have less than a high school education, have lower income and have been at risk of contracting HIV through drug use or heterosexual transmission.

These findings are similar to the South African situation were HIV is found mainly in Black females (Medical Research Council, 2002; STATS SA, 2004; Health Systems Trust, 2004; Dorrington, 2004) who have poor education and low income (STATS SA, 2004; Health Systems Trust, 2004; Dorrington, 2004).

Previously in South Africa, the population group most affected by HIV was found to be younger, i.e. 16-25 year old group (STATS SA, 2004; Health Systems Trust, 2004; Dorrington, 2004) and the predominant mode of transmission is heterosexual intercourse (STATS SA, 2004; Health Systems Trust, 2004; Dorrington, 2004).

The national prevalence of HIV in South Africa has, since 2000, slowed down in the 15-24 age group while the prevalence in the 25-34 age group has been increasing steadily since 1999 (DOH, 2006). Currently, the highest prevalence of HIV is found in the 25-34 age group (59.3%) among females and the 30-39 age group (46.6%) among males (Shisana et al, 2005; SANAC, 2007).

Dental care utilisation and barriers to care for African Amercian Blacks and Whites showed that patients from both racial groups visited the dentist as needed but there was a significant difference with Whites more likely than African American Blacks to attend regularly (Patton et al, 2003; Shiboski et al, 1999). In South Africa, there is a significant difference in oral health utilisation within the different socio-economic groups (Lalloo et al, 2004). The vast majority of the lower socio-economic groups are blacks who traditionally have the least health care access and health care utilisation patterns compared to the whites who are mainly in the middle to high socio-economic group (Lalloo et al, 2004).

2.15 Unmet needs for dental care – the impact of living in a rural area

Heckman et al (1998), in their comparison of barriers to health care among people living with HIV within rural and urban communities, identified unique problems experienced by HIV-positive people in rural areas. They have difficulties in accessing health care as they often need to travel great distances to obtain the health care (Heckman et al, 1998; Shetty, 2004). They also have the risk of being diagnosed late in the disease progression, thus precluding aggressive early intervention of treatment (Heckman et al, 1998). Some patients who are eligible for free treatment do not live close enough to clinics to benefit from these health care services (Shetty, 2004) and they may lack access to or financial resources to utilise personal or public transportation to obtain care in urban areas (Heckman et al, 1998).

In a survey of South African NGO's and organizations active in the field of HIV/AIDS prevention and care programmes, it was found that the majority of the projects focused on prevention (Swartz, 2004). Most projects were based in urban areas, and less delivery of HIV/AIDS services in rural areas (Swartz, 2004).

Some provinces in South Africa are affected by the HIV/AIDS pandemic more than others and disparities also exist at district level within provinces (SANAC, 2007). Surveillance data in the WC Province indicated that the two metropolitan health areas of Khayelitsha and Gugulethu/Nyanga registered HIV prevalence rates of 33% and 29% respectively while the overall prevalence rate for the province was much lower at 15.7%. The National Strategic Plan 2002-2011 reported that people living in rural and urban informal settlements were at highest risk for HIV (SANAC, 2007).

The primary aims of South Africa's HIV & AIDS and STI National Strategic Plan 2007-2011 (SANAC, 2007) are to halve the rate of new HIV infections by 2011 and reduce the impact of HIV and AIDS on individuals, families, communities and society by expanding access to appropriate treatment, care and support to 80% of HIV-positive people and their families by 2011. It has four priority areas: prevention; treatment, care and support; research, monitoring and surveillance and human rights and access to justice. Each priority area is linked to a number of specific goals of which there are 18 in total. Goal 6 aims to enable people with HIV and AIDS to lead healthy and productive lives and a specific objective of this goal is to strengthen the health system and remove barriers to access by increasing the proportion of health facilities that provide comprehensive HIV care and building the capacity of health care workers and managers. The extent to which oral health care is included in this broad defintion of "comprehensive care" is not clearly enunciated. However, it is evident that national government has begun to take steps to address the resource needs of people living in rural areas who need HIV care and ought to ensure that all national and provincial HIV/AIDS projects and policies have a rural component as well as a clear oral health plan built into them.

Currently, all CHC's offer

- comprehensive care at subsidised rates which are determined by the individual's age, level of income and number of dependents
- voluntary counselling and testing (VCT) facilities
- VCT for all newly diagnosed pregnant mothers with the option of mother-to-child transmission prevention in the form of Zidovudine monotherapy free of charge if the mother tests HIV positive and is not eligible for HAART

Unfortunately, only some CHC's have dedicated HIV/AIDS clinics where HAART drugs are issued free of charge to eligible candidates.

2.16 Stigma and disclosure as barriers to regular dental care for people living with HIV/AIDS

According to the South African law, people living with HIV have the legal right to privacy and if the person chooses to disclose their HIV status they must be given information pertinent to disclosure and informed of the consequences that will follow disclosure (Doyal, 1997; Hartnell and Maile, 2004). In terms of the Health Professions Act (Act No 56 of 1974), no health care worker may verbally or in writing divulge any information which ought not be divulged regarding the ailments of the patient, except with the express consent of the patient or, in the case of a minor, with the express consent of his or her guardian, or in the case of a deceased patient, with the express consent of his or her next of kin or the executor of his or her estate (Hartnell and Maile, 2004).

Confidentiality is very important to people living with HIV because of the widespread HIV/AIDS related stigma and discrimination (Doyal, 1997; Furber et al, 2004). HIV/AIDS related stigmas entrench social isolation and discrimination against people living with HIV (Doyal, 1997; Kalichman and Simbayi, 2003), which is widespread in all countries including South Africa (Lapidus and Sandler, 1997).

AIDS-related stigma is "the process of devaluation of people living with or associated with HIV/AIDS" (Furber et al, 2004). Fear of a poor quality of life and inevitable death constitute one of the factors that amplify stigma, however this factor can be lessened once HIV is perceived as a chronic but treatable condition (Furber et al, 2004). People who are living with HIV face various problems such as being rejected by loved ones and by health professionals including the dentist, being confronted with homophobic reactions, losing employment and having difficulty finding housing and most importantly living in fear of a future made uncertain by illness (Charboneau et al, 1999, Furber et al, 2004).

Although health care workers are ethically and legally required to keep all patient information confidential, disclosing their HIV status remains a sensitive barrier to overcome for the patient living with HIV/AIDS, yet is an essential step to obtain the benefits of care and support (Hartnell and Maile, 2003). Several studies have shown that a significant number of participants do not disclose their HIV status to caregivers including dentists (Robinson et al, 1993; Barnes et al, 1996; Craven et al, 1996; Charbonneau et al, 1999).

In a survey of people living with HIV in Britain, half of the participants who revealed their HIV status were refused care and most delayed or avoided dental care due to fear of negative attitudes from dental staff or being refused treatment (Craven et al, 1996).

Godin et al (1999) suggested the habit and the experience of treating people living with HIV was another factor explaining the intention of the dentist to provide care for people living with HIV (Manz et al, 1994; Lapidus and Sandler, 1997; Godin et al, 1999). A sufficient level of enthusiasm and acceptance would initiate treatment of the first person living with HIV and this experience and increased confidence may result in an increased enthusiasm for and acceptance to treating more people living with HIV (Manz et al, 1994; Lapidus and Sandler, 1997).

The dental profession was one of the first health care groups to respond to the challenges of HIV/AIDS (Kleinman, 1997; Zabos and Trinh, 2001). Universal precautions in the control of infection have become the norm in standard dental care (Zabos and Trinh, 2001). Dental professionals are continually updated, educated and trained on HIV related issues through dental schools, continuing education courses and AIDS education and training centres (Terry et al, 1994; Greene et al, 1997; Zabos and Trinh, 2001). Within the resource-stressed setting of a developing country such as South Africa, however, this training and continuing education is not universal.

HIV related attitudes and willingness to treat people living with HIV were best predicted by age and the system of delivery of care in which the dentist was employed (Craven et al, 1996, Lapidus and Sandler, 1997). Older dentists were found to be more likely to have HIV-related continuing education courses (Craven et al, 1996), however younger dentists were found to have treated more HIV infected patients than older dentists (Lapidus and Sandler, 1997).

Socio-economic status is thought to be an influencing factor regarding discrimination. Most dentists who treated the lower socio-economic group believed it was ethically wrong to refuse treatment to HIV positive patients (Lapidus and Sandler, 1997). Some dentists consider it their right to refuse treatment to people living with HIV, especially when the risks are high (Barr et al 1989, Manz et al 1994; Lapidus and Sandler, 1997), however, refusal to treat a patient after the patient has disclosed their HIV status is discrimination (Greene et al, 1997; Chikte and Naidoo, 2000).

Naidoo and Govan (2003) state that current scientific evidence indicates that knowledge of the HIV status of the patient does not provide additional protection to oral health care workers. Testing for HIV should only be suggested if the degree of protection it affords the oral health care worker is substantially more than the potential harm it may cause the patient (Chikte and Naidoo, 2000). A comprehensive HIV/AIDS policy guideline with a guide for clinical management by Naidoo and Govan (2003) was published by the South African Dental Association and is an attempt to educate oral health care workers on dealing with HIV in the clinical setting.

Manz et al (1994) reported that dentists indicated that they felt they should have the right to decide whether to treat people living with HIV and felt they have a professional, rather than a legal obligation to treat people living with HIV. The willingness of the dentists to treat was found to be high, though the dentist's confidence was said to diminish if they were not aware of or had no access to the HIV status of the patients (Manz et al, 1994). Similar results were obtained by Bennet et al (1995) where the majority of their participants said they would treat people living with HIV whose needs where within the scope of their practice.

Most dental associations have a code of ethics that states that dentists have an ethical and legal obligation to treat all patients regardless of their HIV status (Zabos and Trinh, 2001; Crossly, 2003). However, Crossley (2004) reported that dentists consider themselves to be at higher risk for stigmatisation compared to other health care workers should they treat people living with HIV/AIDS due to the surgical nature of their work and the higher risk of blood-borne disease. In this qualitative exploration of dentists, it was found that the most common fear reported was related to dealing with staff fears. The second most common fear was their personal risk for contracting HIV.

2.17 Conclusion

Oral lesions are important manifestations of HIV/AIDS. They are early clinical features of HIV disease and form part of the WHO and CDC staging schemes. Oral health profoundly impacts on quality of life and oral lesions in HIV/AIDS causes morbidity such as the inability to swallow with resulting poor nutritional intake as well as oral pain. Health care workers such as nurses trained in HIV/AIDS care, general practitioners and dentists may deliver oral health care for people living with HIV/AIDS.

The literature shows that people living with HIV/AIDS have negative experiences when seeking dental care. Due to fear of discrimination or being denied care, patients may choose not to disclose their status and studies abroad have established that high levels of unmet needs for oral health care prevail among people living with HIV.

Socio-demographic factors have been identified that constitute barriers to oral health care among people living with HIV/AIDS, and these are female gender, non-caucasian race, lack of medical insurance, unemployment, low income, low level of education and living in a rural versus urban area. Poor physical and mental health is also reported to be barriers to obtaining care.

Universal precautions protect health care workers from contracting blood-borne disease and therefore dentists do not have to alter the standard of care delivered to HIV-positive patients. Disclosure of status does not afford the dentist any additional protection.

Confidentiality remains important to people living with HIV/AIDS because of the widespread HIV/AIDS-related stigmatisation and discrimination. Studies show that disclosing HIV status may negatively impact on obtaining care or negate the quality of care the individual receives. Dentists with experience in treating people with HIV were more likely to treat new patients. Some dentists hold the opinion that they should have a choice whether they wish to treat people living with HIV/AIDS or not. This is not in agreement with the ethical mandate of the dentist as established in professional codes to uphold his/her duty to care for all patients.

CHAPTER 3: AIMS AND OBJECTIVES

3.1 Aim

To determine barriers to oral health care for people living with HIV.

3.2 Objectives

1. To identify the barriers to oral health care for people living with HIV in KZN and the WC provinces with respect to:
    i) Predisposing factors: age, race, rural versus urban settlement, marital status, educational level and migration patterns.
    ii) Enabling factors: employment, household income, medical aid and dental insurance, distance to service and mode of transport.
    iii) Illness level, duration HIV status known and its impact on the ability to secure care.

2. To determine the dental care experiences of people living with HIV in KZN and the WC:
    i) How prevalent is the need for oral health care?
    ii) How was this health care need met?
    iii) Do people living with HIV disclose their status?
    iv) What are the reasons for not disclosing HIV status?
    v) How do people living with HIV perceive the attitudes of the health care workers regarding their status?

3. To make recommendations to improve the accessibility and acceptability of the provision of oral health care for people living with HIV.

CHAPTER 4: RESEARCH DESIGN AND METHODOLOGY

This chapter discusses the research design and methodology used in the study. It describes the development of the research instrument and data collection method. While keeping a focus on the objectives, consideration was given to the methodology employed by other researchers who carried out similar studies.

4.1 Study design

The study design of this research project has aspects of both quantitative and qualitative research paradigms. Quantitative research involves the use of numerical measurement and statistical analyses of measurements. It views reality as a consistent phenomenon that can be observed and measured. The advantage of a quantitative approach is that it places a great premium on objectivity and reliability and encourages replication. Quantitative research is ideal for theory and hypothesis testing (Saunders et al, 2000; Cooper et, al 1998).

Qualitative methods allow researchers to understand how the subjects of research perceive their situation and their role within their context. It allows researchers to elicit in-depth information on their subjects by talking to them or observing them. Qualitative data consists mainly of descriptions of people or places, or of conversations. Such information cannot be easily handled by statistical procedures (Katzenellenbogen et al, 1997; Saunders et al, 2000).

In the present study, a cross-sectional study design was chosen utilising a self-administered questionnaire and semi-structured interviews to collect data. Consenting participants were requested to complete a self-administered, structured questionnaire and cases were selected to participate in semi-structured interviews.

4.2 Selection of study population

The study population consisted of people living with HIV attending HIV clinics at selected sites in the WC and Kwazulu Natal. Nonprobability sampling was employed to select the sites where participants were enrolled using convenience sampling. However, when logistical problems were encountered (lack of room space or staff support) and in the event that these problems could not be circumvented, the target was foregone and more patients were recruited from another site within the same province.

4.3 Study population and sampling

The sampling of the participants from the clinics was by means of convenience sampling and a sample size of 20 participants per site was targeted. Regarding the question of the sample size required, it was necessary to have a knowledge of estimates of the variance ($\sigma^2 = \pm 5$) which was available from similar studies. According to the calculation, it was discovered that 15 participants per site would be adequate given a 95% confidence interval and a standard deviation of 10 (derived from similar studies); however, where possible, more participants were enrolled based on availability.

Inclusion Criteria

- People living with HIV
- Attending a pre-selected CHC or regional hospital
- 18 years or older
- Written, informed consent obtained

4.4 Measurement

The selection of the type of measurement instrument depends on:

- the population under investigation
- the type of information needed
- the environment of data collection
- the type of observer /interviewer
- time, money and human resources available (Katzenellenbogen et al, 1997)

Semi-structured interviews

In semi-structured interviews the interviewer follows a list of themes and questions with opportunities for open-ended discussion of items and is both quantitative and qualitative (Saunders et al, 2000).

Individual Interviews

According to Katzenellenbogen et al (1997) individual interviews have the following advantages:

- personal contact can facilitate response and quality information
- can be done when participants have low literacy and cannot fill in self-administered forms
- can collect data from people who are otherwise not reachable (e.g. people from rural areas or informal areas)

Disadvantages of individual interviews were noted as:

- time-consuming and expensive
- interpersonal dynamics may interfere with data collection (e.g. suspicion)
- interviewer variation affects reliability

The semi-structured individual interview approach was selected. The data collection process consisted of a self-administered questionnaire with closed-ended and some open-ended questions and a semi-structured interview with closed and open-ended questions for some participants. This allowed for a better understanding of the social functioning of the participant and provided a greater level of understanding of the processes that affected the results without compromising the reliability of the findings (Katzenellenbogen et al, 1997; Saunders et al, 2000).

Development of the Instrument

1. A *list of variables* based on the study objectives was made and wittled down based on common themes to obtain a menu of core variables.
2. *Succinct questions* were formulated based on these variables. The questions were formulated in a closed-ended manner where the answers were either 'yes' or 'no', a number or a choice of one group of a predetermined, multiple answer categories. Closed questions encourage quicker, more standardized data collection, but may limit responses or inhibit the respondent (Katzenellenbogen et al, 1997).
3. The *sequence of the questions* were carefully planned to ensure logical flow. Basic demographic questions were asked first, followed by experiences questions and then the perception questions. This allows the interviewer to build trust with the respondent prior to asking the sensitive questions. Figures 1 and 2 graphically depict the sequence of the questions and the structure of the questionnaire.
4. *Questions were broken up into component parts* to provide a fuller, more meaningful answer. Leading and loaded questions were avoided or rephrased where necessary and the questions were checked to see if they were mutually exclusive. The questions were checked for simplicity, conciseness and specificity.
5. At this stage, all the questions were evaluated to determine whether some form of *introduction or explanation* was necessary prior to asking the question and whether prompts (a statement or question which triggers a response, usually without actually suggesting what the answer should be) ought to be used at all. It was decided that some questions needed an introduction/explanation and others required prompts. Some questions were left open-ended so that participants could choose more than one of a predetermined menu of choices as the answer categories were not mutually exclusive.
6. The *layout and design of the questionnaire* was formatted so that there was clarity and errors were minimized. It was typed in double spacing, 12' font to ensure it would be clearly read.
7. Questionnaires were translated from English into Zulu by Mrs T. Khawula, Afrikaans by Dr H. Pienaar and Xhosa by Mr S. Vanqa.
8. The *measurement scale of each variable* was identified. This enabled the researcher to plan adequately for the analysis stage.

9. A *coding spreadsheet* was prepared in MS Excel and variables were converted into numbers and categories to enable rapid capturing of questionnaire data.
10. The *coded database was imported into the SPSS programme* for analysis.

The questionnaire had several sections that contained open-ended and closed-ended questions and was self-administered (Williams, 1996; Marshall and Rossman, 1995); all participants, however, had access to the researcher to clarify any uncertainties they had about answering the questions. The questionnaire elicited demographic information about the participants, recorded their dental care experiences, as in similar studies by Jacobson et al (1989), and determined the dental care experience of people living with HIV (Terry et al, 1994). Each completed questionnaire was tagged with a serial number to identify the site and the number of the questionnaire in the series. The participant remained anonymous to ensure that the questionnaires could not be traced to any respondent (Terry et al, 1994).

Interviews

Participants were randomly chosen to expand on their experiences in a semi-structured interview. This elicited in-depth information on the individual experiences of participants. The interviews were conducted by one interviewer, the principal researcher. Thirteen interviews were conducted. The language spoken depended on the preference of the participant and interviews were conducted in English, Afrikaans, Zulu and Xhosa. No interpreters were employed as the principal researcher; Dr Turton is fluent in English and Zulu and speaks conversational Afrikaans and Xhosa as well.

Pilot survey

A pilot survey was conducted on 10 participants to determine the accuracy of the questionnaire. Piloting the questionnaire tested how long the interview took and it gave the researcher the opportunity ensure that the questions were clear and unambiguous. Grammatical changes were made to some questions. It was decided that question 8, 9, 11, 12 and 16 needed an introduction/explanation while prompts were necessary for questions 16, 18, 20, 21, 22, 23 and 24.

Figure 1: Flow-chart of structure and sequence of questionnaire

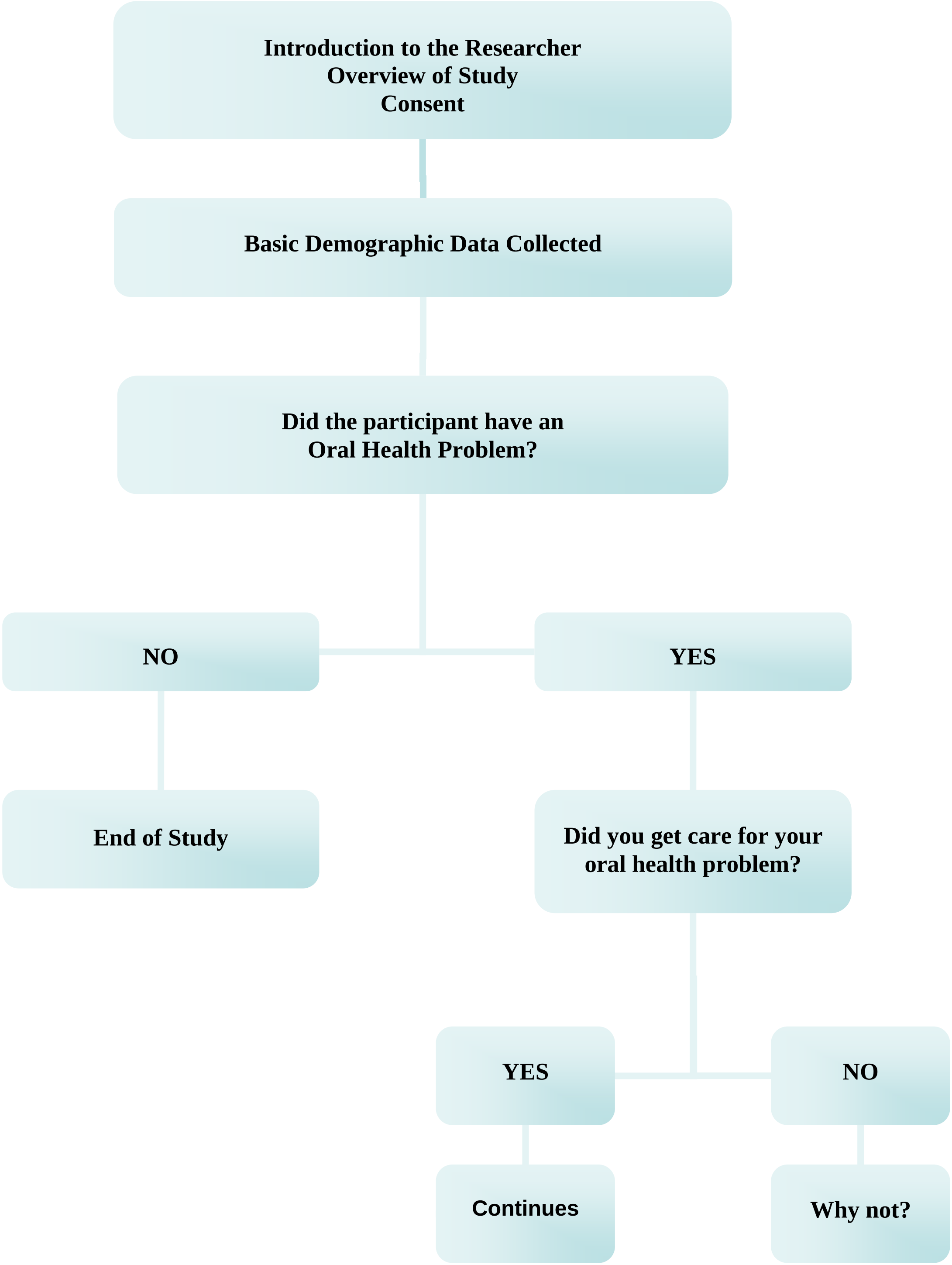
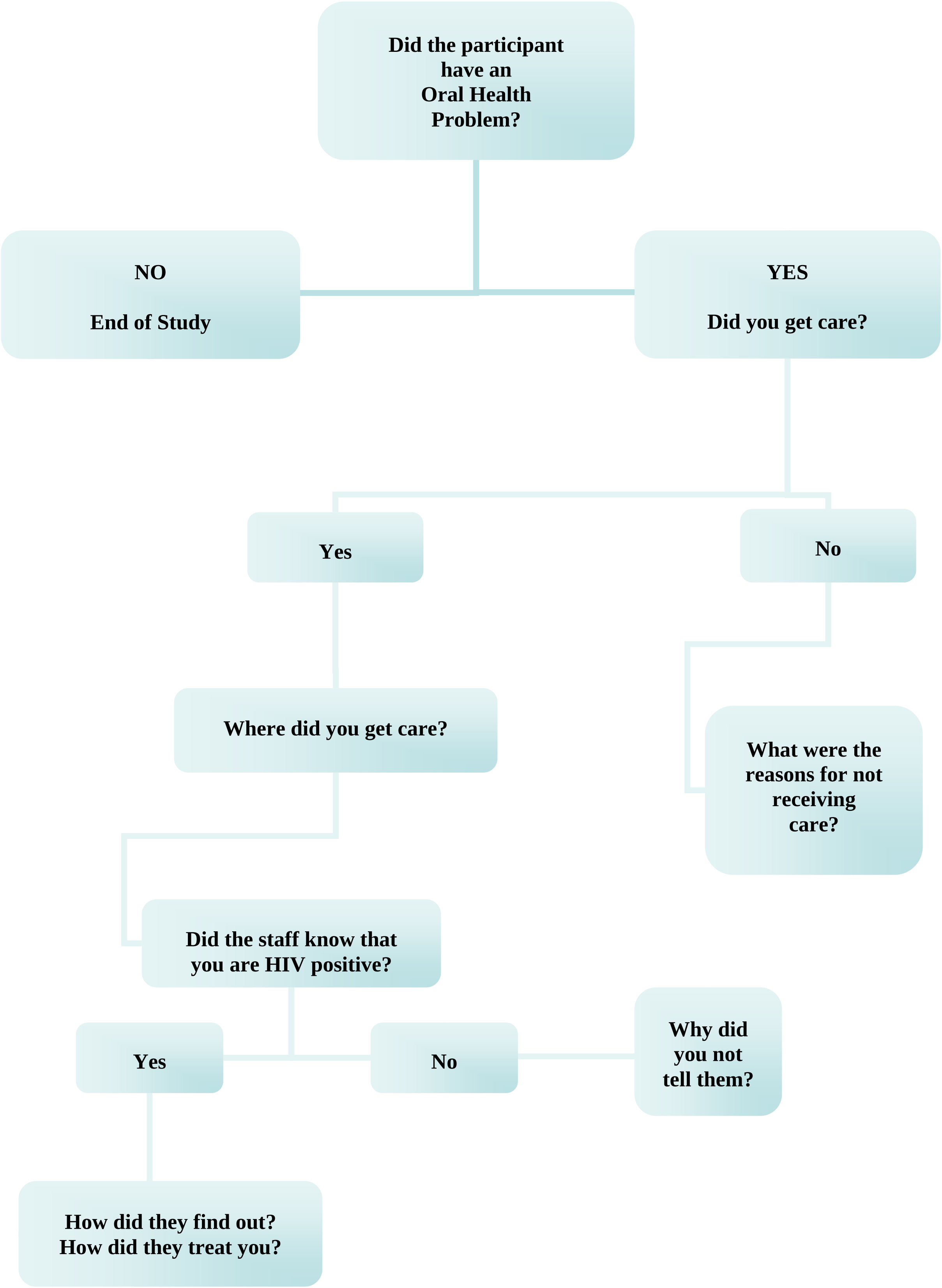


Figure 2: Flow-chart of structure and sequence of questionnaire



4.5 Data Analysis

Questionnaire data were categorized, coded and then entered into the computer. The data was captured in Excel. Basic descriptive analysis was done using the Excel programme. The database was imported into SPSS to perform complex stastical analyses.

Descriptive statistics were used to describe the demographic factors. The independent t-test was used to determine correlation between the scale variables (*age* and *duration status known*) of the provincial cohorts and the significant relationships were reported. The Mann-Whitney *U* test was used to compare the nominal and the ordinal variables of the provincial cohorts to determine if they were alike or different.

To determine the influence of a host of factors on the outcome variable, "Did you get care or not?", a binary logistic regression model was employed. This technique was selected because it reports the effect of any given variable on the outcome of the dependent variable while taking the effect of all the other variables in the model into account as well.

Interviews were captured in writing and were analysed for themes which were pertinent to the study. Extracts of the interviews were utilised to expand qualitatively on quantitative findings in the study.

4.6 Establishing contacts

The provincial Departments of Health of the WC and KZN and the Municipal health district managers respectively granted permission for the research to be conducted at various hospitals and clinics distributed in the two provinces. The researcher visited the recruitment site. Individuals attending HIV and Voluntary Counselling and Testing (VCT) clinics located at Community Health Centres (CHC's) and regional hospitals in both provinces were approached and offered the opportunity to anonymously participate in the study. The nature of the study was explained to them verbally and in writing and they were requested to sign or indicate with an X that they had understood the nature of the study and voluntarily consented to participate in the study. The researcher collected the questionnaire on completion.

The recruitment sites were selected with the aim to get a similar rural versus non-rural distribution per province. The following study sites were selected in KZN: Bruntville (16), Durban (8), Empangeni (23), Estcourt (20), Folweni (16), Greytown (12), Kokstad (12), Mooiriver (6), Mpendle (34), Odidini, (11), Richmond (30), Vryheid (16), Bulwer (10), Eskaweni (14), Howick (17). The following sites were selected in WC: Beaufort West (8), Cape Town (42), Delft (28), Worcester (23), Hout Bay (3), Khayelitsha (38), Mitchells Plain (16), Paarl (21), Stellenbosch (11).

4.7 Approval by Ethics Committee

The research proposal was approved by the Senate Research Ethics Committee of the University of the WC (Appendix 8). Permission to conduct the study at the various hospitals, clinics and institutions were obtained from the Health Departments and Municipal Heads of the WC and KZN provinces.

Informed consent (Appendix 2) was obtained in writing from the participants in the language that they chose. Participation in this study was entirely voluntary and the participants were allowed to withdraw from the study at any time should they wish to do so. Anonymity was achieved by not using the participant's names on the questionnaire and the questionnaire was recorded as a serial number (Appendix 2).

4.8 Conclusion

This study was a survey among HIV positive people attending selected CHC and regionals hospital HIV clinics in KZN and WC provinces. The sample consisted of people living with HIV that were 18 years or older and who had given written, informed consent.

CHAPTER 5: RESULTS

5.1 Introduction

This chapter presents the results of this study and the data is presented in tabular or graphical form to ensure ease of reference. In most cases, data is presented separately for each provincial cohort as well as for the entire study population.

The findings from analysis of the questionnaires will be discussed in the following sections: sampling and response rates; age; race; average duration status known; geographical distribution of participants; marital status; educational level; migration patterns; employment; household income; medical aid; and travelling. The experiences of people who had oral health problems and received or did not receive care are explored.

Thirteen interviews were conducted – seven individual interviews in KZN, one group interview of five participants in KZN and six individual interviews in WC.

5.2 Study population

The sample consisted of 435 HIV positive adults. 190 participants were from WC and 245 were from KZN. Figures 3-7 show the location of the centres where respondents were recruited and Figures 4-7 the number of completed questionnaires that were accepted for analysis from each centre.

Figure 3: Map of KZN showing all the sites where participants were enrolled

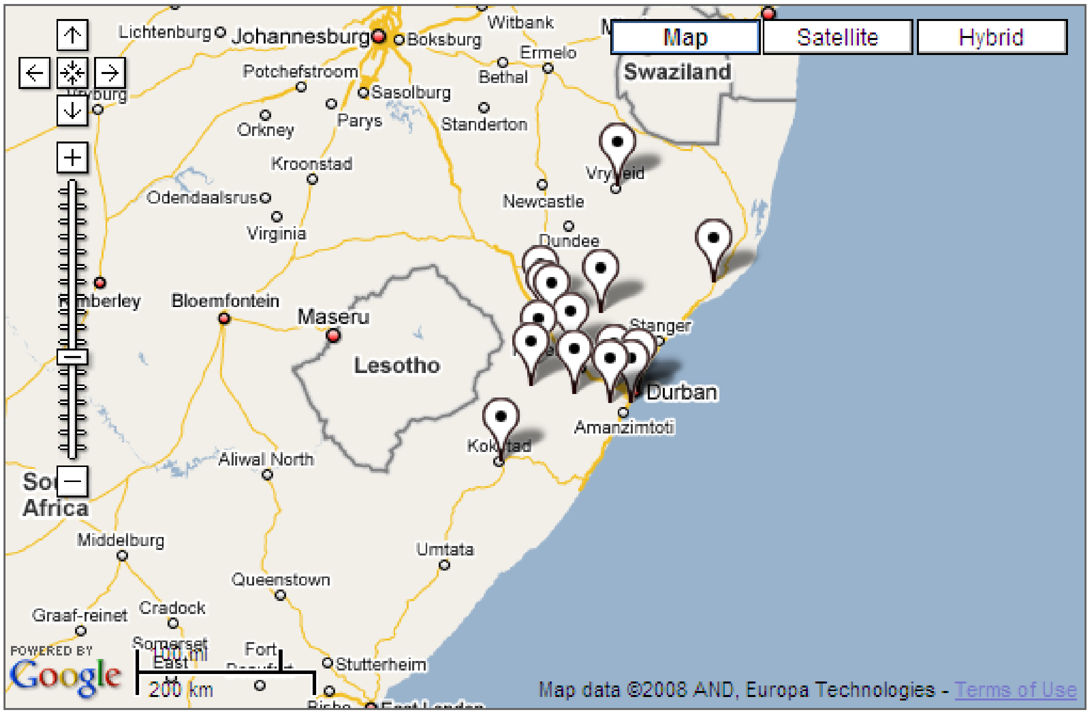


Figure 4: Map of northern KZN showing the number of participants enrolled per site

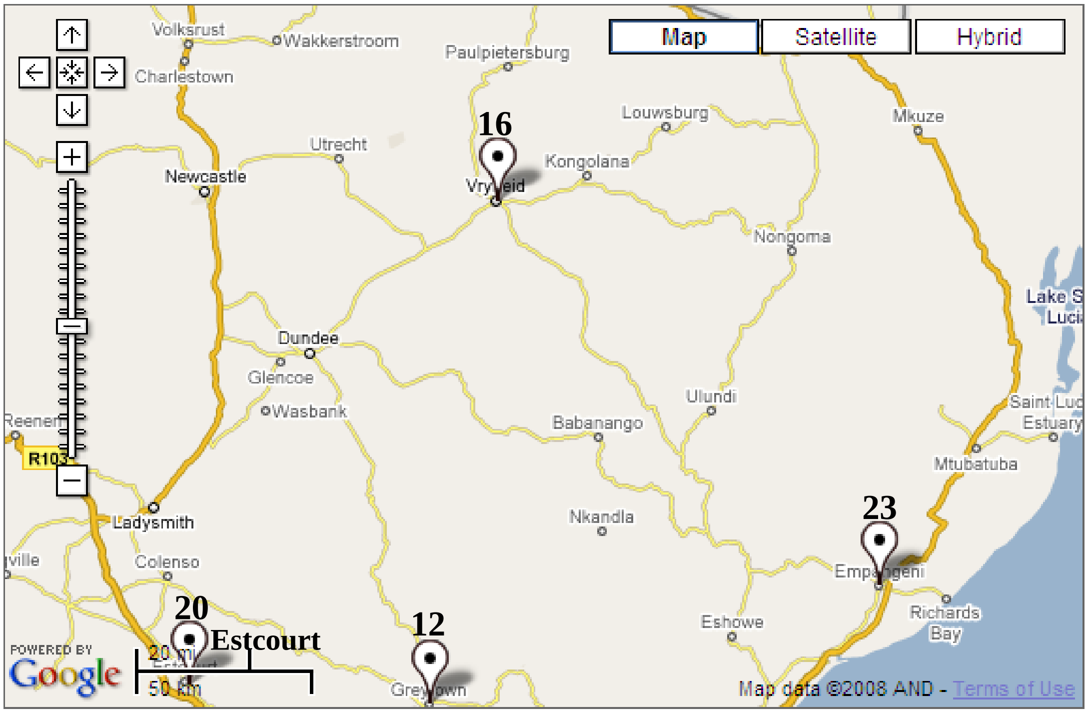


Figure 5: Map of southern KZN showing the number of participants enrolled per site

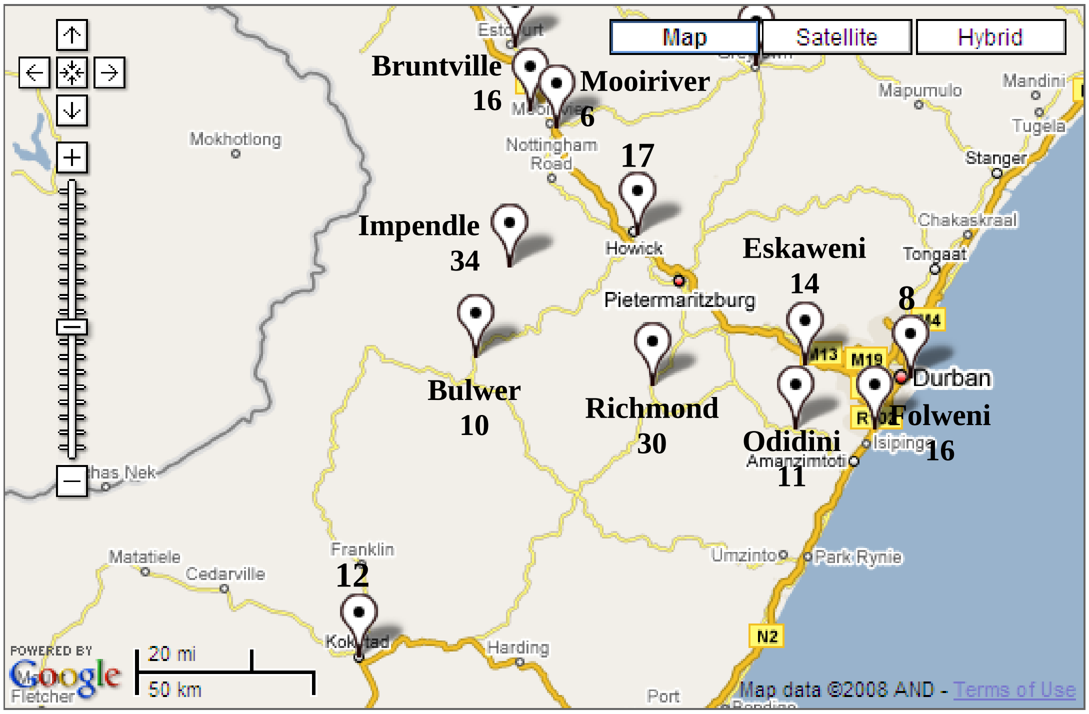


Figure 6: Map of WC showing the number of participants enrolled per site

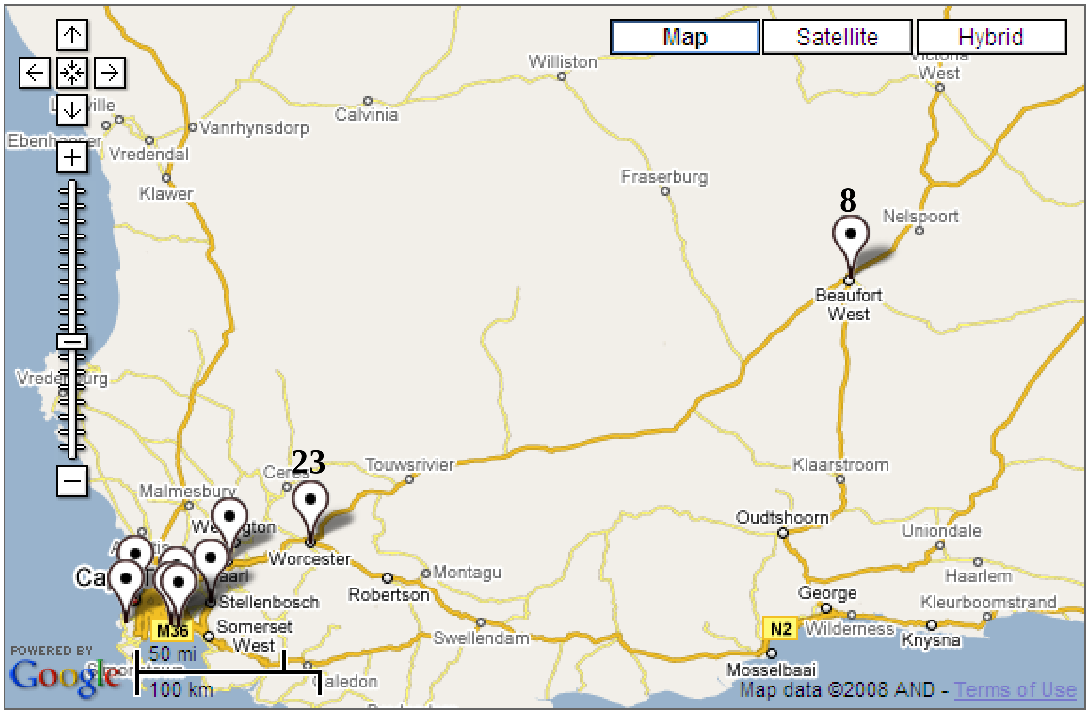


Figure 7: Map of WC showing the number of participants enrolled per site

5.3 Sampling

There were 467 individuals that participated in the study and completed the questionnaires; however, 32 questionnaires were incomplete and excluded from the analysis. The final sample size was 435. Figures 8 and 9 show flow-charts that show how many participants completed each leg of the study.

Figure 8: Summary of response rates

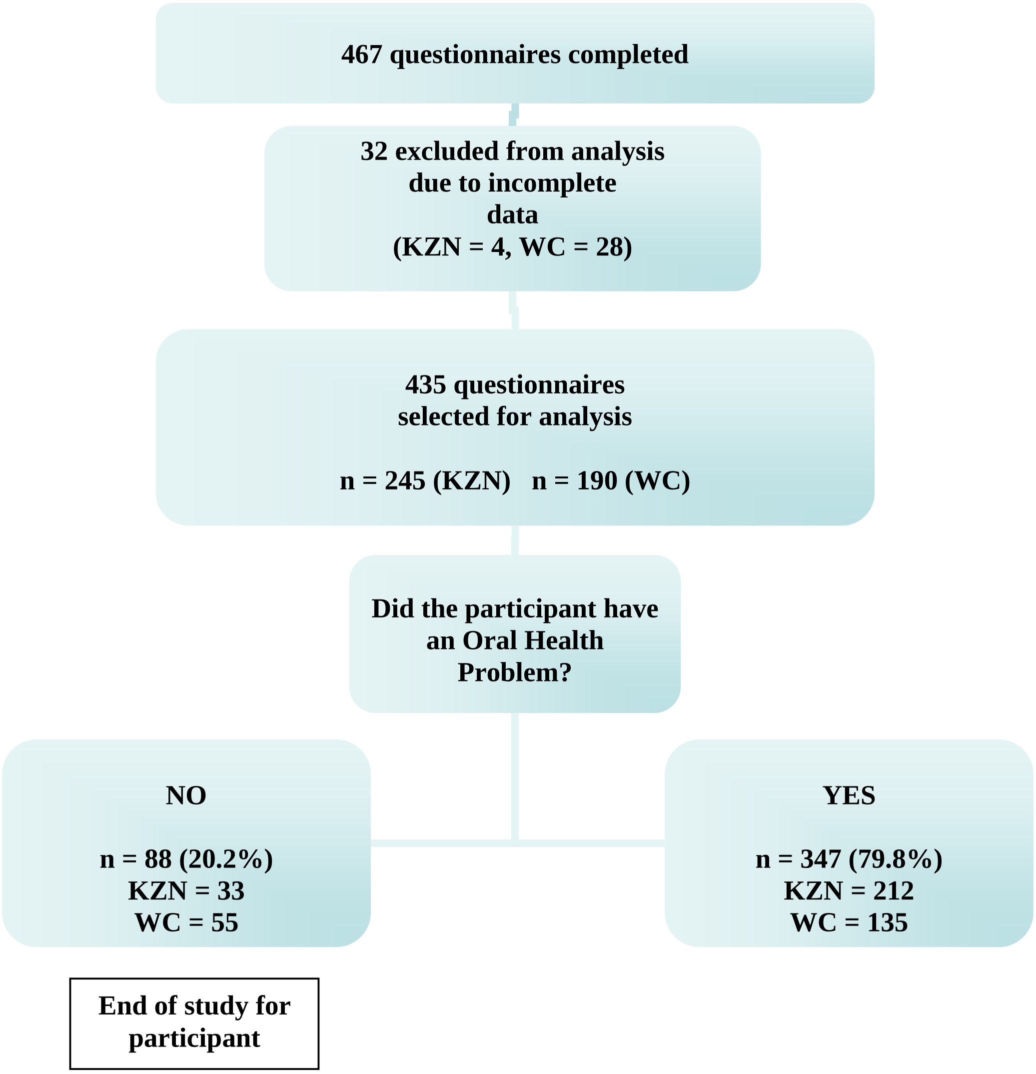
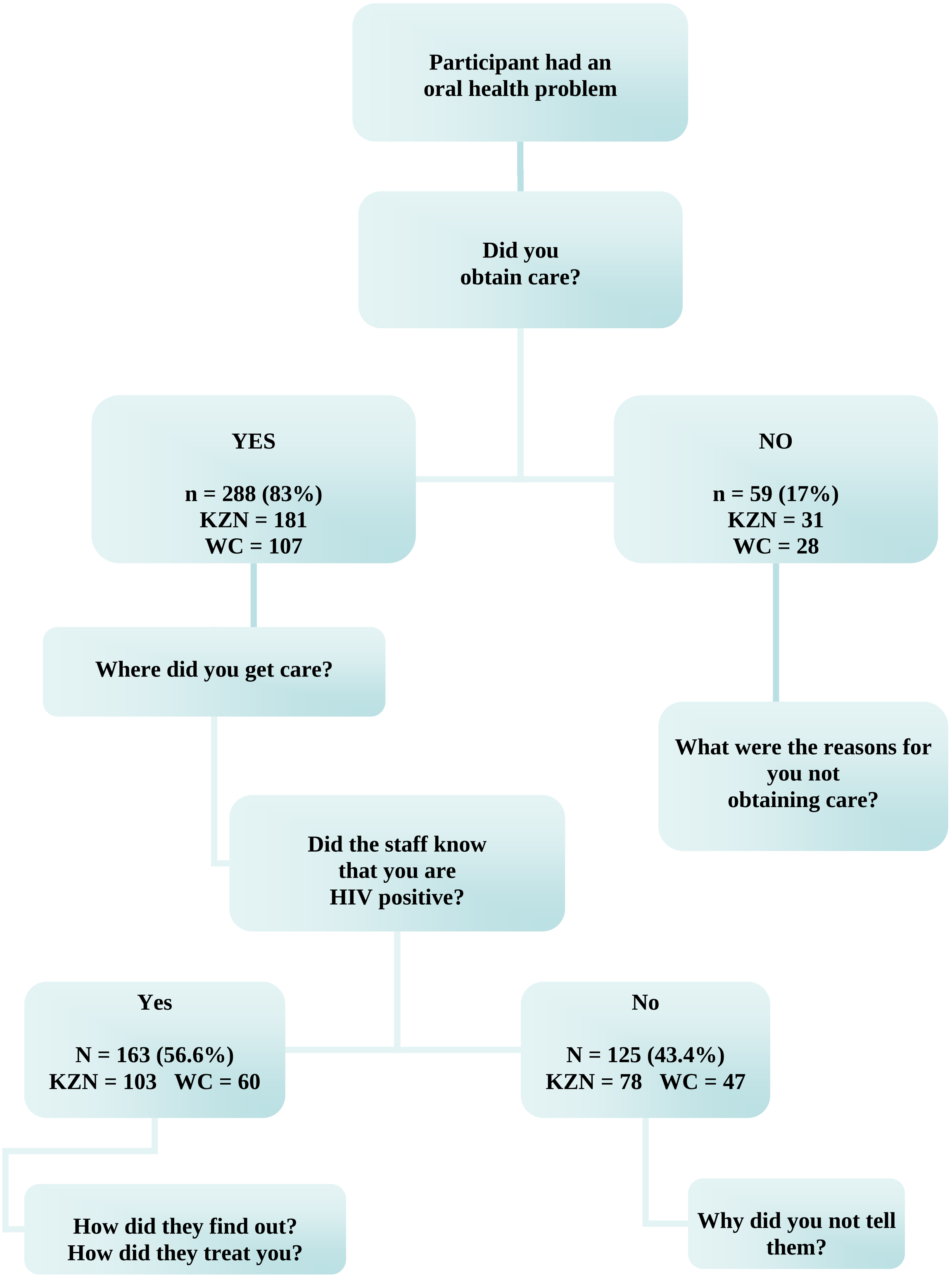


Figure 9: Summary of response rates



5.4 Age

The average age of the study population was 32.55 years. The average age of participants in KZN was 30.84 years (range 18-54), while WC participants had an average age of 34.75 (range 18-73). The difference between the mean ages of the two provincial cohorts was statistically significant (*t* = -4.844, df = 433, p <0.01, two-tailed). Table 2 summarises this data by age, gender and ethnic group.

Table 2: Age per gender group for the two provincial cohorts

	KZN			WC			
Data	**Male**	**Female**	**Total**	**Male**	**Female**	**Total**	**Total**
Number of participants (n)	89.00	156.00	245.00	61.00	129.00	190.00	435.00
Mean Age	30.97	30.72	30.81	37.80	33.19	34.67	32.49
Max of Age	51	54	54	64	73	73	73
Min of Age	19	16	16	10	10	10	10
Standard Deviation of Age	8.06	7.61	7.76	10.34	8.41	9.30	8.67
95% Confidence Interval	-	-	29.84-31.78	-	-	33.35-35.99	-

5.5 Race and Gender

There were 89 males and 156 females from KZN that participated in the study, while 61 males and 129 females from WC completed questionnaires. The KZN cohort represented just over half (56.32%) of the total study population (Table 2). Figure 10 demonstrates the racial distribution of the entire study population with annotations for gender distribution for the black and coloured groups.

The majority of the participants were black females (56.78%) followed by black males (27.36%). Overall, 65.52% of the participants were female. There was a difference between the KZN and WC cohorts in terms of racial distribution which was statistically significant (Z = -4.859, p < 0.01).

Figure 10: Racial distribution for the entire study population

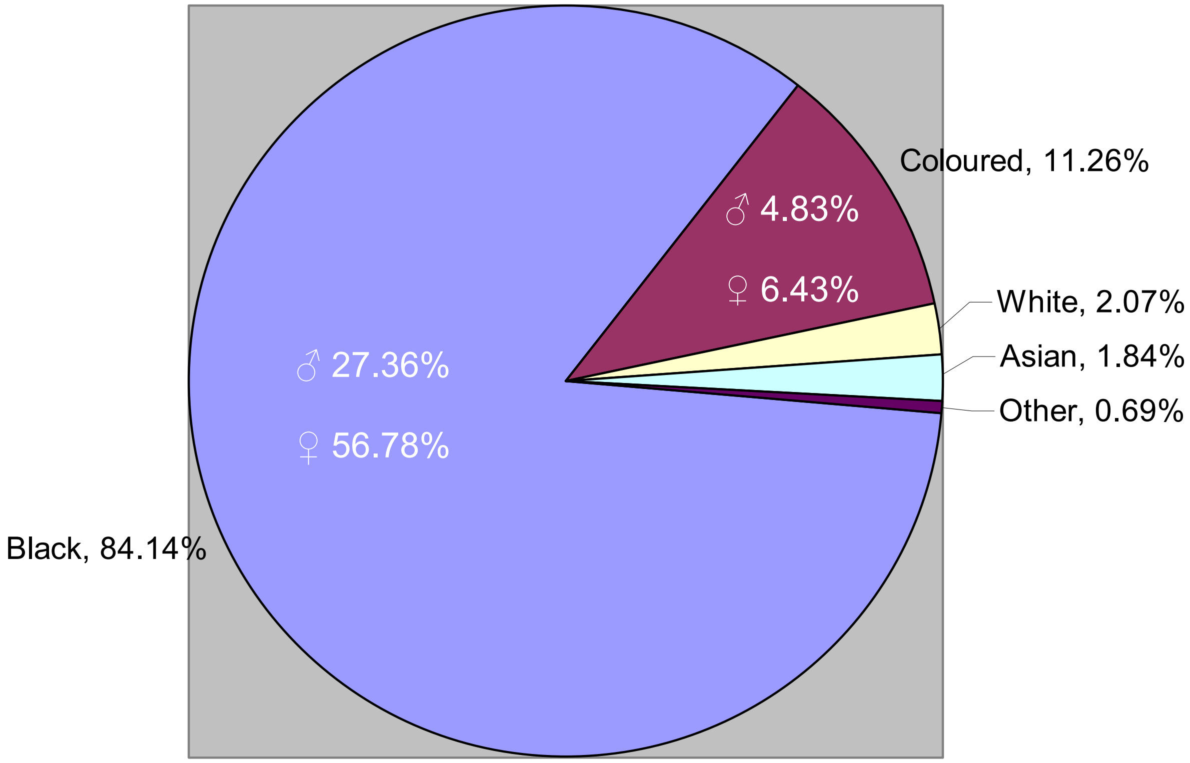
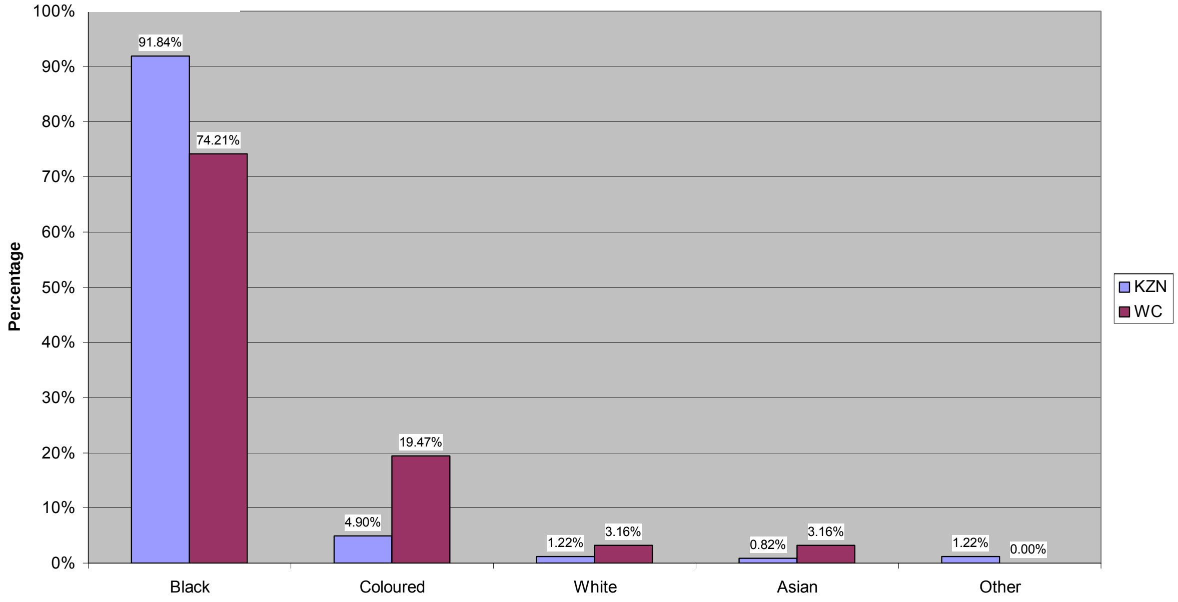


Figure 11 demonstrates the difference in racial distribution between the KZN and WC cohorts.

Figure 11: Racial distribution per provincial cohort



5.6 Average duration status known

For the entire study population, the average duration of status known was 33.21 months (range 1-168, StdDev 27.61). In the KZN cohort, the average duration of status known was 25.73 months (95% CI 22.76-28.70) and for the WC cohort, 42.85 months (95% CI 38.68-47.02). Using an independent t-test, the difference was found to be statistically significant ($t = -6.737$, df = 433, $p < 0.01$).

Table 3 shows summary of the mean, range and standard deviation for the duration of months the participant had known their HIV/AIDS status per gender group per provincial cohort.

Table 3: Mean, range and standard deviation for duration status known per provincial cohort

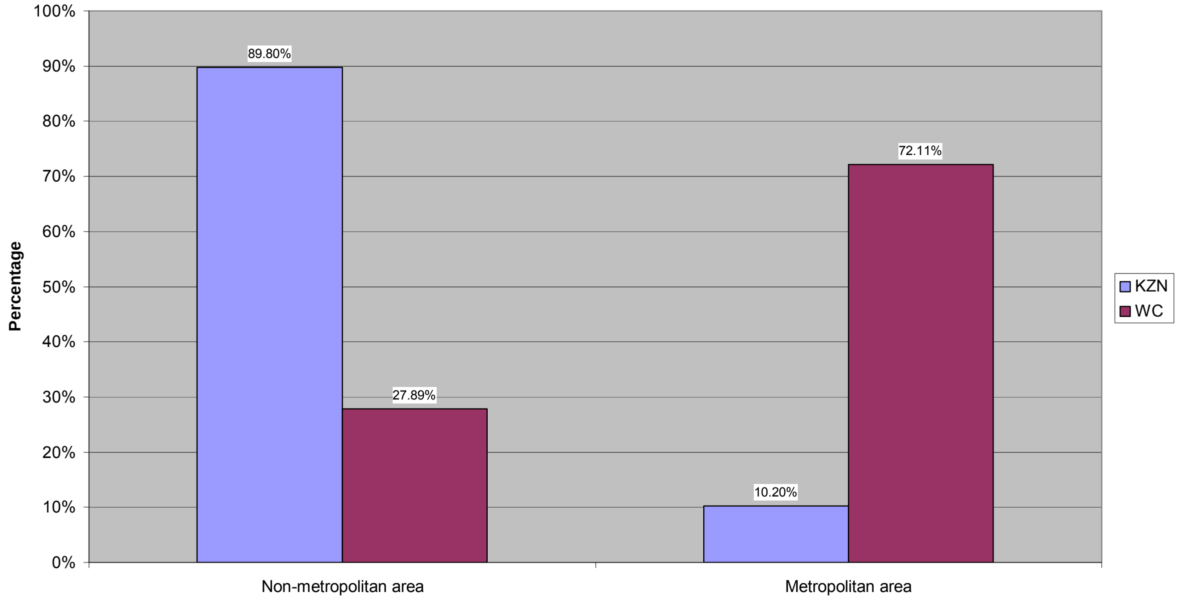
Data	KZN			WC		
	Male	Female	Total	Male	Female	Total
Mean duration status known	26.82	25.10	25.73	35.92	46.13	42.85
Min of duration status known	1	1	1	10	2	2
Max of duration status known	96	84	96	60	168	168
StdDev of duration status known	25.90	22.41	23.70	17.82	32.96	29.31
95% Confidence Interval			22.76-28.70			38.68-47.02

5.7 Summary of Regional Distribution of Participants

It should be borne in mind that individuals often travel from their home towns to obtain care. Even though convenience sampling was utilised to select recruitment sites and it was aimed to recruit participants at a similar ratio of rural versus urban sites in each province, it is erroneous to assume that participants live in the town where the CHC is situated (where the participant was recruited) and therefore participants were asked to disclose where they lived.

These areas were classified as metropolitan versus non-metropolitan areas (Figure 12) according to municipal regional classification. The majority of the KZN participants lived in non-metropolitan areas (89.80%) while the inverse was true for WC (72.11%). The difference in the groups was statistically significant ($Z = -13.230$, $p < 0.01$).

Figure 12: Regional distribution of participants per provincial cohort

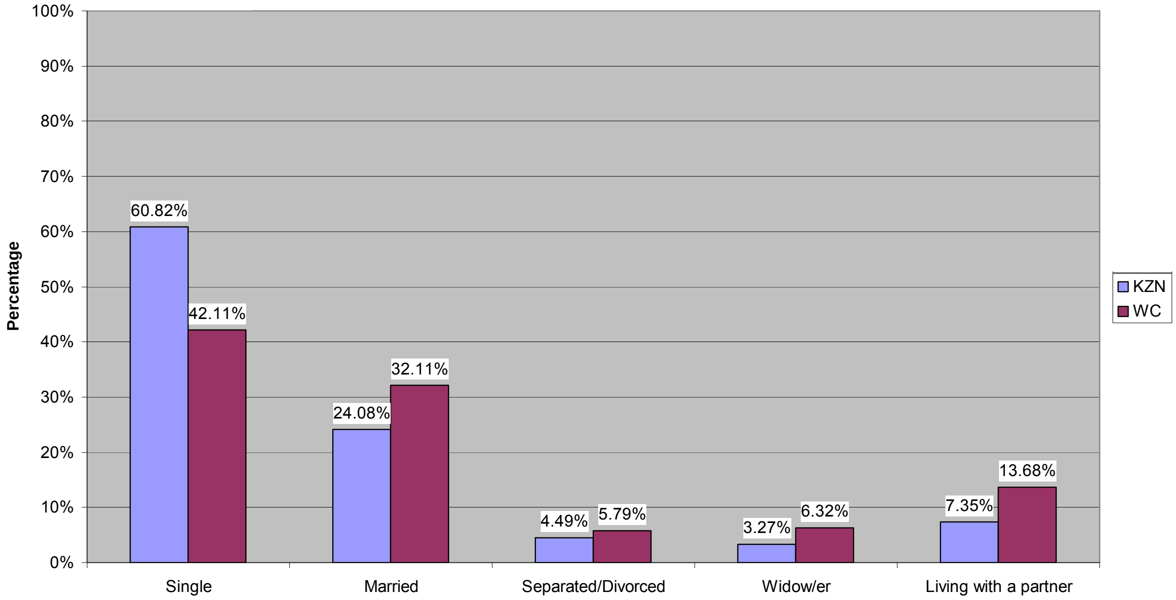


5.8 Marital Status

The majority of the participants were single (N = 229, 53%) with the next largest group being married (N = 120, 27.59%). A tenth of the participants were living with a partner while a minority were separated/divorced (5.06%) or widowed (4.6%).

More participants were single in the KZN cohort (60.82% versus 42.11% for WC), but in the WC, more people were living together (13.68%) than in KZN (7.35%). The differences between the provincial cohorts were statistically significant ($Z = -3.991$, $p < 0.01$) and is depicted in Figure 13.

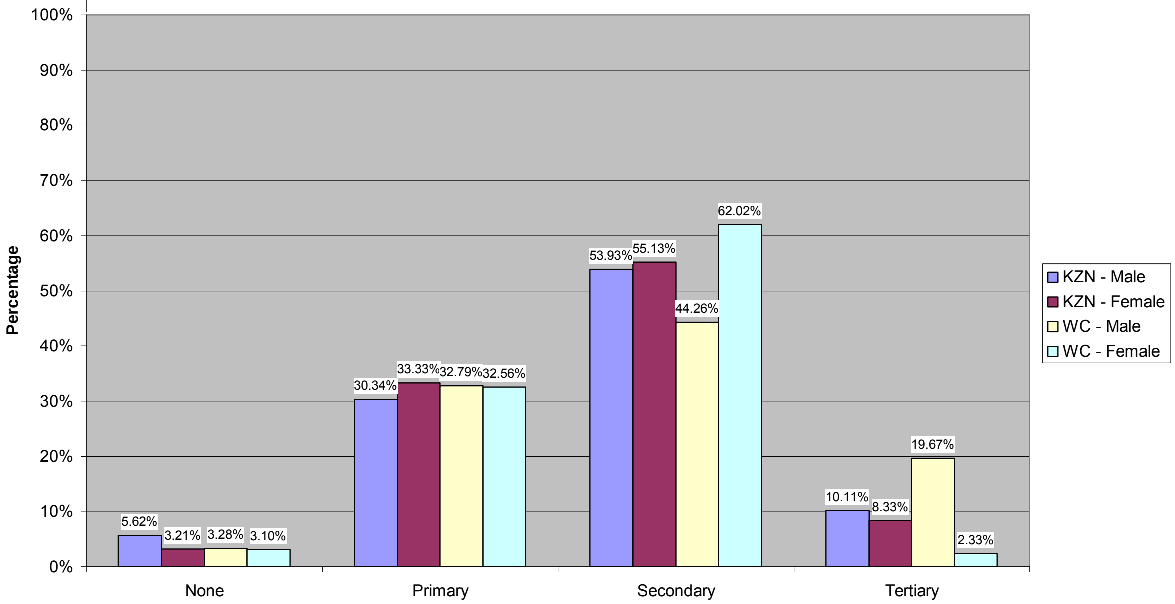
Figure 13: Marital status per provincial cohort



5.9 Educational Level

Over half had attained at least secondary level education (55.4%) and almost a third attained primary level eduction (32.41%). Only 3.68% had no education at all. Figure 14 demonstrates this data.

Figure 14: Highest level of education obtained per gender for each provincial cohort



Although a small difference can be observed between the number of participants with tertiary versus secondary level of education in the males of the WC cohort versus males in the KZN cohort, this difference was not statistically significant and overall, there was no difference between the provincial cohorts in terms of educational level (Z = -0.22, p = 0.982).

5.10 Migration Patterns

The participants were asked whether they had moved into the area in the past two years (Table 4).

Table 4: Summary for "Did you move recently?" for KZN and WC cohorts

Move Recently	KZN (%)	WC (%)
Yes	23.67	25.79
No	76.33	74.21

The differences between the KZN and the WC cohort were not statistically significant (Z = -0.568, p = 0.612). Those participants who had moved (N = 107) were asked to supply reasons for moving. Table 5 summarises the reasons why participants moved – only 3.43% of participants moved because of health reasons (Table 5).

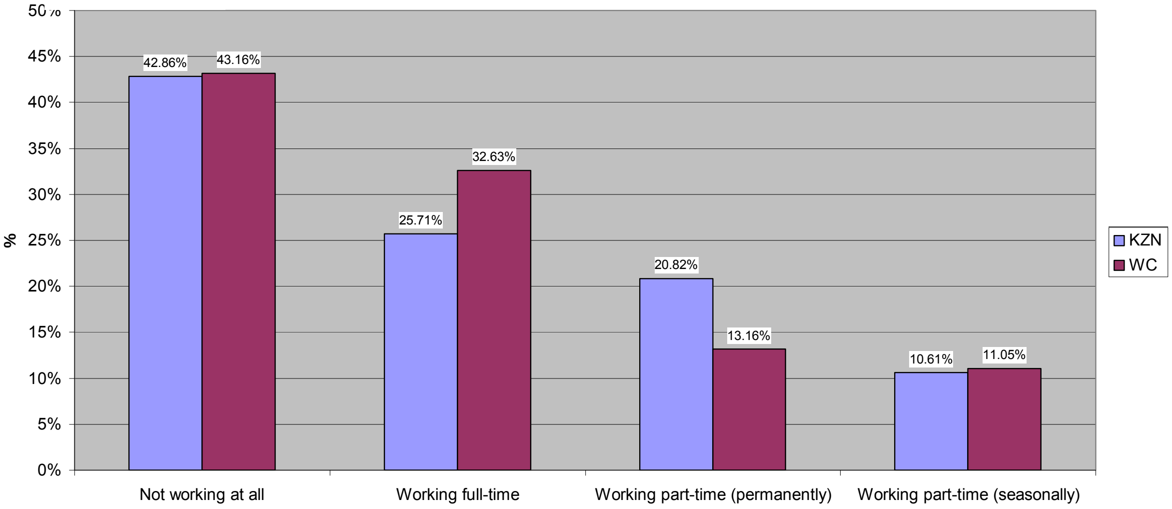
Table 5: Summary of reasons for moving

Reason for moving	KZN (%) n = 58	WC (%) n = 49	Total (%) n = 107
Unspecified ("Other")	36.14	35.78	35.97
Birth Place	29.72	4.59	17.99
Work	16.47	40.37	27.62
Marriage	4.42	0.46	2.57
Forced Relocation	3.61	0.00	1.93
Better quality of life	1.61	0.00	0.86
Housing	1.61	5.05	3.21
Treatment for HIV	**1.61**	**0.00**	**0.86**
Evicted from farm	1.20	0.00	0.64
Political Unrest	0.80	0.00	0.43
Better Health Services	**0.80**	**1.38**	**1.07**
Nearer to clinic	**0.80**	**1.38**	**1.07**
Followed Family	0.80	2.75	1.71
Studying	0.40	7.34	3.64
Illness	**0.00**	**0.92**	**0.43**

5.11 Employment

Nearly half of the participants in both cohorts were unemployed in the previous year. There was no significant difference in the observations between the two cohorts (Z = -0.650, p = 0.516) and the unemployment levels per provincial cohort is depicted in Figure 15.

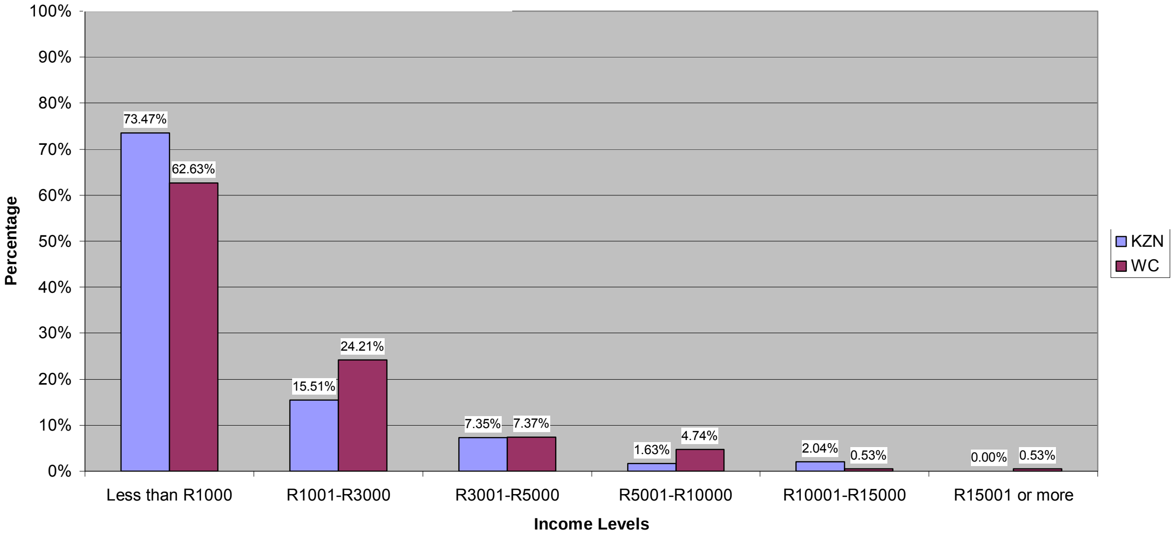
Figure 15: Unemployment levels per provincial cohort



5.12 Household Income

Table 7 shows the income levels for the entire study population. Although the provincial cohorts appeared quite similar, the participants in KZN earned less than WC participants with nearly three quarters (73.47%) earning less than R1000 pm while only 62.63% of their WC counterparts earned less than R1000 (Figure 16). This difference was statistically significant with Z = -2.255 and p = 0.024.

Figure 16: Household income per provincial cohort



5.13 Medical Aid

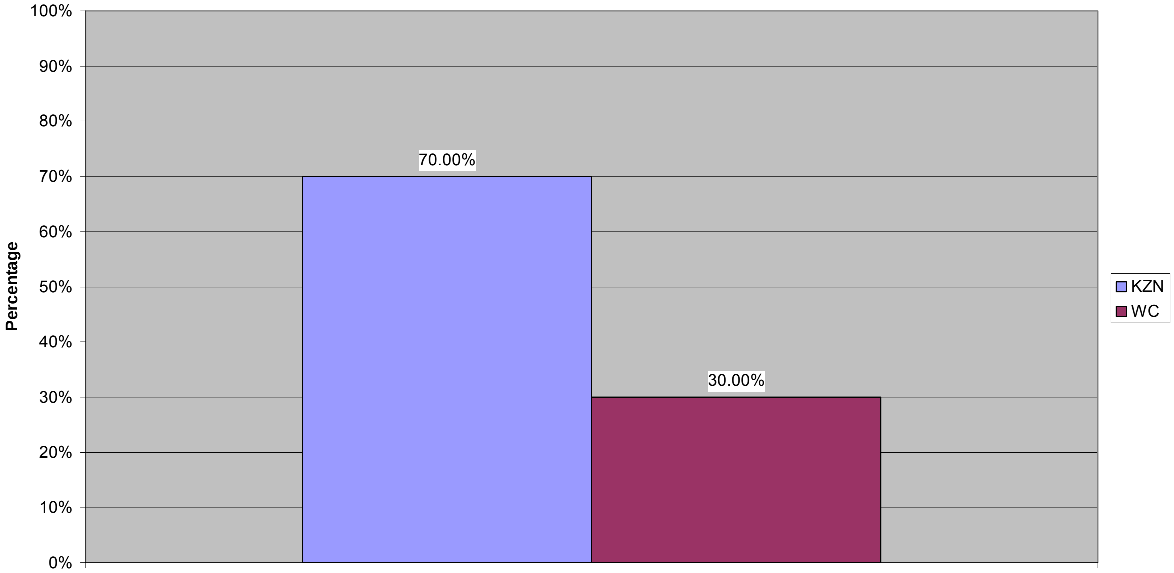
Almost 85% of participants did not have medical aid (Table 6). Although 17.96% had medical aid in KZN versus 13.16% in WC, this difference was not statistically significant (Z = -1.358, p = 0.174).

Table 6: Summary of possession of medical aid per provincial cohort

Medical Aid	KZN (%)	WC (%)	Total (%)
Has medical aid	17.96	13.16	15.86
No medical aid	82.04	86.84	84.14

Those who had medical aid (N = 69 with N_{KZN} = 44 and N_{WC} = 25) where asked whether their medical aid covers dental treatment. Just over a third (35.06%) reported that their medical aid did not cover dental treatment. Figure 17 compares the values for the respective cohorts in terms of medical schemes covering dental treatment.

Figure 17: Dental insurance for those participants who had medical aid per provincial cohort

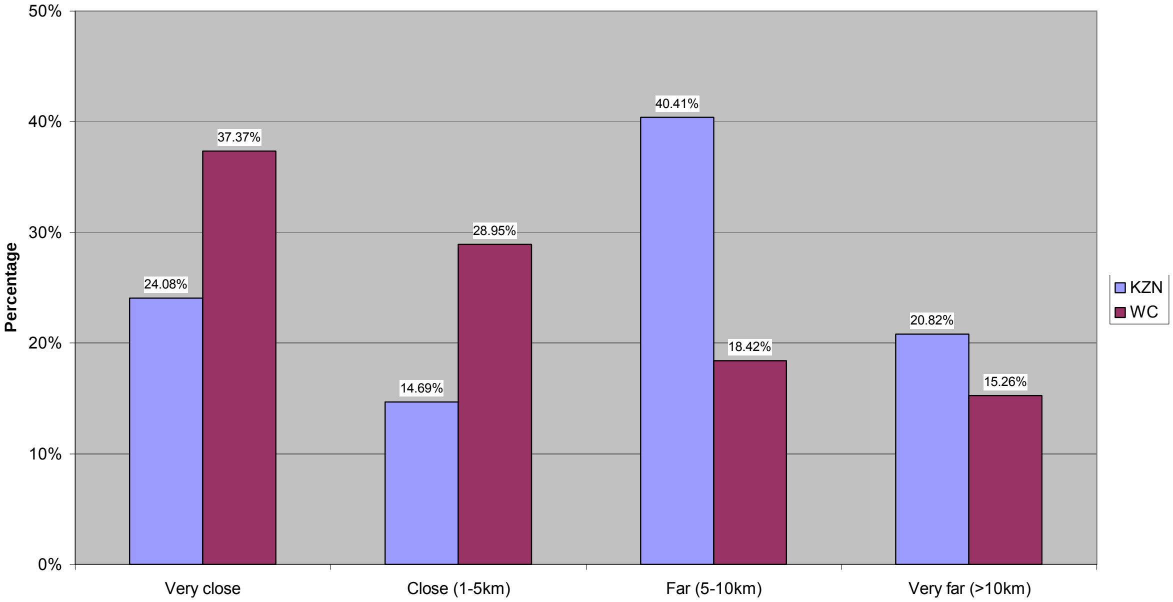


5.14 Travelling

Distance from oral health service

Participants were asked to choose the option that best describes the distance they stay from the clinic. The results are summarised in Figure 18.

Figure 18: Distance to nearest oral health service per provincial cohort

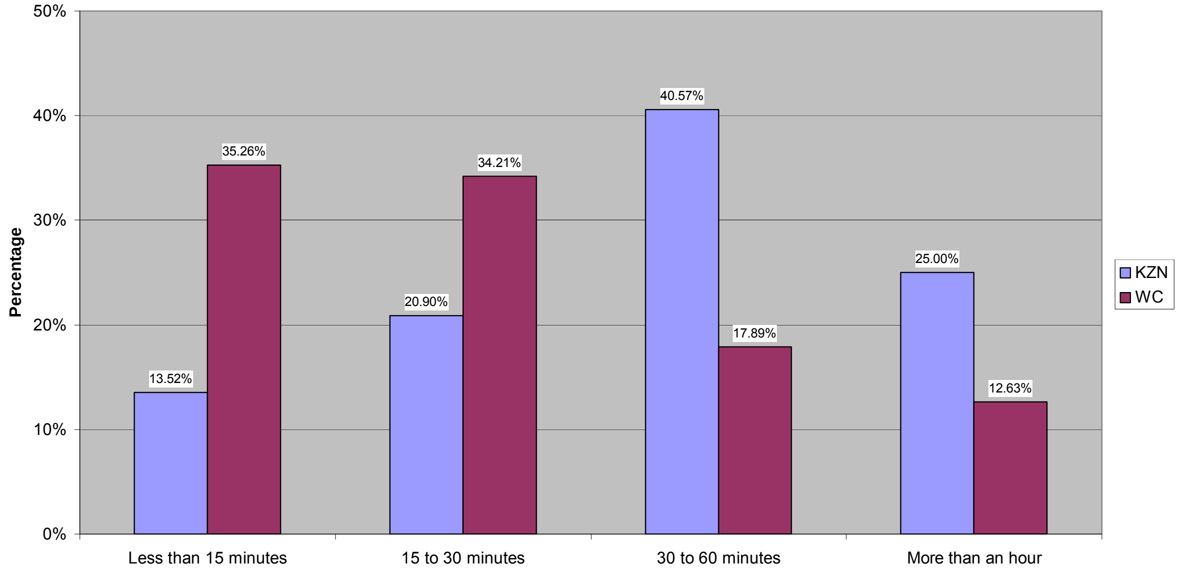


In KZN, 40.41% of participants lived very far from the nearest dental clinic, dental hospital or dentist while in comparison the majority of the WC participants lived very close (37.37%) and close (28.95%) to the nearest clinic. This difference was statistically significant (Z = -4.406, p <0.01).

Travelling time to oral health service

In KZN, a quarter of patients travel more than an hour to reach the health care centre. In contrast, only 12.53% of participants in WC reported that it took more than an hour to travel (Figure 19). This difference was statistically significant (Z = -6.877, p <0.01) as well.

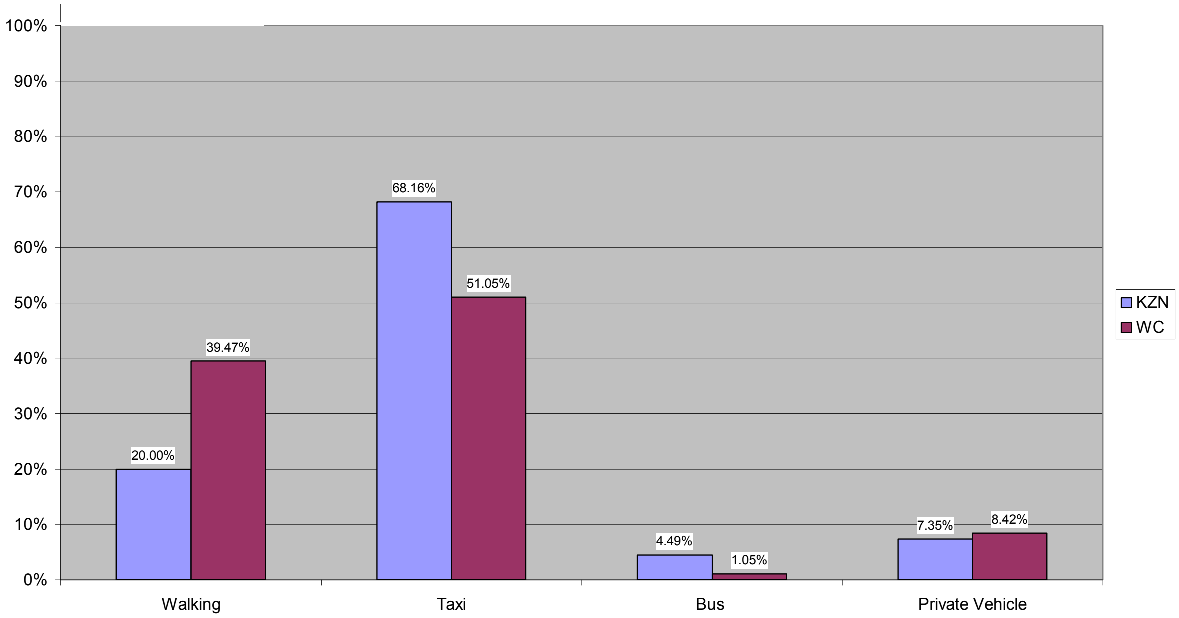
Figure 19: Time taken to travel to nearest oral health service per provincial cohort



Means of transport

There were differences between the provincial cohorts in terms of means of transport (Figure 20). In KZN, 68.16% of participants used taxis in comparison to 51.05% in the WC. More participants in the WC had access to private vehicles and many of them walked (the latter was in keeping with the finding that more than a third of WC participants lived close to their oral health service). This difference was statistically significant ($Z = -3.869$, $p < 0.01$).

Figure 20: Means of transport per provincial cohort



5.15 Oral Health Problems among Participants

Table 7 reports the prevalence of oral health problems for the entire study population.

Table 7: Summary of prevalence of oral health problems per provincial cohort

Did you have an oral health problem?	**KZN (%)** **n = 245**	**WC (%)** **n = 190**	**Total (%)** **n = 435**
Did have oral problem	86.53	71.05	79.77

Of the entire study population, 79.77% (N = 347) reported experiencing oral health problems during their illness. Table 12 shows that 86.53% of the KZN participants and 71.05% of the WC participants had an oral health problem. The participants from the WC cohort reported 15.48% less oral health problems than the KZN cohort. This difference was statistically significant (Z = -3.981, $p < 0.01$).

5.16 Obtaining care

Table 8: Summary of obtaining care in those who had oral health problems (n = 347)

	KZN	**WC**	**Total (%)**
Did obtain care	85.38%	79.26%	83.00

Of the 347 participants who had oral health problems, 288 participants obtained care (N_{KZN} = 181, N_{WC} = 107). In KZN, 85.38% of participants received care and 79.26% of the WC participants obtained care. This represents 83% of the total study group. Although the WC cohort obtained care less frequently than the KZN cohort, the difference between the KZN and WC cohorts was not statistically significant (Z = -1.477, p = 0.144).

Of the patients who received oral care (N = 288; N_{KZN} = 181; N_{WC} = 107), participants were asked:

- Where did you get care?
- Did the staff or health care workers where you were getting treatment know that you are HIV positive?
- If no, why did you not tell them?
- If yes:
  - How did the health care worker discover your status?
  - How did you experience their attitude regarding your HIV status?

Of the patients who did not get care (n = 59), participants were asked:

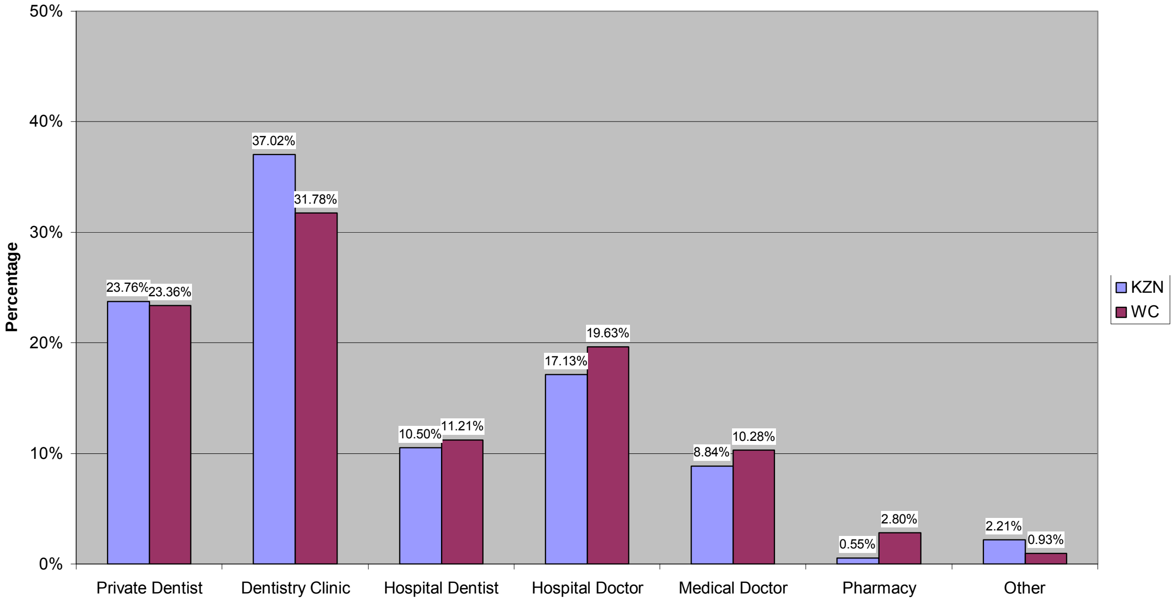
- What was the reason for you not receiving dental treatment since you were diagnosed as HIV positive?

5.17 Participants who obtained care

5.17.1 Site of care

Almost three quarters of all participants were treated in the public sector (73.26%) either by a dentist at a dental clinic (35.07%), by a hospital dentist, a hospital-based doctor or a general practitioner. Figure 21 shows the respective values per provincial cohort. A medical doctor provided the care for 9.38% of participants while a few sought care at a pharmacy (1.39%). Almost 2% sought care at other, unspecified sources. There was no statistical difference between the provincial cohorts in terms of the site where care was obtained (Z = -0.727, p = 0.464).

Figure 21: Site where care obtained (n = 288)



5.17.2 HIV status disclosure

More than half of all the participants (56.59%) reported that the staff or health care worker had known their status. The observed difference between the provincial cohorts was not significant (Z = -0.468, p = 0.639). Table 9 supplies the reasons why the health care workers had or had not known the status of the participant.

Table 9: Did the staff or health care workers where you were getting treatment know that you are HIV positive?

Did they know your status?		KZN (%) N = 181	WC (%) N = 107	Total (%) N = 288
No	No, they did not ask so I did not tell them	34.25	42.06	37.15
	No, I did not tell them even though they asked	8.84	1.87	6.25
	Subtotal	**43.09**	**43.93**	**43.40**
Yes	Yes, they asked me and I told them	28.73	21.50	26.04
	Yes, I told them even though they did not ask me	14.92	11.21	13.54
	Yes, the doctor who sent me told them	10.50	9.35	10.07
	Yes, they found out in some other way	2.76	14.02	6.94
	Subtotal	**56.91**	**56.08**	**53.59**

5.17.3 Reasons for undisclosed status[1]

Of the 181 KZN respondents who obtained care for their oral health problem, 78 remained undisclosed during the visit while of the 107 WC respondents who obtained care, 47 remained undisclosed.

A fourth of KZN respondents who did not disclose their status did not do so because they were fearful of what the health care worker would think of him/her (25.66%). In the WC, a fourth of participants feared loss of confidentiality if they disclosed their status (24.65%).

The results are shown in a frequency table (Table 10).

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[1] For questions 22 (reasons for not disclosing), participants were allowed to choose more than one answer when determining what the reasons were for not disclosing their HIV status. The responses were counted and percentages were calculated by using the total number of responses as denominator and not N (i.e. the total number of participants who remained undisclosed)..

Table 10: Reasons for not disclosing HIV status

Statement	**KZN**		**WC**	
	n	**%**	**n**	**%**
I was afraid to tell them because of what they would think of me being HIV positive.	39	25.66	15	19.48
I was afraid to tell them because they would tell others.	17	11.18	19	24.68
I did not tell them because they did not ask.	24	15.79	12	15.58
I did not think it was important to tell them that I was HIV positive.	21	13.82	3	3.90
I did not see a reason to tell them about my HIV status.	13	8.55	10	12.99
I was just receiving dental treatment.	14	9.21	3	3.90
I was in so much pain that I did not consider telling them about my HIV positive condition.	18	11.84	1	1.30
I was afraid they would refuse to treat if they knew I was HIV positive.	6	3.95	14	18.18
TOTAL	**152**	**-**	**77**	**-**

5.17.4.1 Events leading to disclosure of status[2]

Of the 181 KZN respondents who obtained care for their oral health problem, 103 disclosed their status while of the 107 WC respondents who obtained care, only 60 disclosed their HIV status.

Table 11 summarises the responses to the question which asked the participant how the health care worker had discovered his/her status. In KZN, 23.84% of the responses were that someone else had told the health care worker about the participant's HIV status and a similar response was obtained in the WC (23.94%). In both provinces, almost a fifth of participants thought that it was important for the health care worker to know their status and disclosed their status for that reason (15.89% and 14.41% for KZN and WC respectively); some disclosed their status even though they were not asked (10.6% in KZN and 15.49% in WC).

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[2] For question 23 (events leading to disclosure), participants were allowed to choose more than one response. The responses were counted and percentages were calculated by using the total number of responses as denominator, and not N.

Table 11: Events leading to disclosure of status

Response	KZN		WC	
	n	%	n	%
I told them because they asked me about my HIV status	37	24.50	10	14.08
I told them even though they did not ask about my HIV status	16	10.60	11	15.49
I told them because I thought it was important for them to know	24	15.89	8	11.27
I told them even though I did not think it was important for them to know	3	1.99	4	5.63
My relative/s (father, mother, brother, sister, cousin) advised me to tell them so I told them.	13	8.61	6	8.45
My relative/s (father, mother, brother, sister, cousin) told them.	10	6.62	5	7.04
My partners (wife, husband, boyfriend, girlfriend) advised me to tell them so I told them.	10	6.62	7	9.86
My partners (wife, husband, boyfriend, girlfriend) told them.	9	5.96	5	7.04
The doctor that sent me to them advised to tell them so I told them.	12	7.95	8	11.27
The doctor that sent me to them told them.	17	11.26	7	9.86
Total	**151**	**-**	**71**	**-**

5.17.4.2 How did you experience their attitude regarding your HIV status?[3]

The 163 participants who had disclosed their status were asked to select the answer that best described how they had experienced the attitude of the health care worker where they obtained care. Table 12 summarises the responses that were obtained.

In KZN, 26.2% of participants reported a negative experience while 39.81% of their WC counterparts reported the same. The most frequent positive response was that the participant felt welcome. Of the negative responses, the most frequent ones were that the "treatment was rushed" and that the "staff was unsupportive".

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[3] For question 24 (the attitude of the health care worker following disclosure of status), participants were allowed to choose more than one response. The responses were counted and percentages were calculated by using the total number of responses as denominator, and not N.

Table 12: Attitude of health care worker toward patients who had disclosed their status

Response	KZN		WC	
	n	%	n	%
They made you feel unwelcome.	15	2.85	14	4.32
They made you feel welcome.	59	11.2	34	10.49
They seemed unhappy to treat you.	7	1.33	10	3.09
They seemed happy to treat you.	48	9.11	22	6.79
They were very worred about being infected by you.	11	2.09	10	3.09
They did not show concern about being infected.	47	8.92	21	6.48
The treatment was rushed.	25	4.74	20	6.17
The treatment was not rushed.	23	4.36	10	3.09
They were impatient.	8	1.52	6	1.85
They were patient.	47	8.92	25	7.72
They were unhelpful.	5	0.95	11	3.4
They were helpful.	49	9.3	23	7.1
They were unsympathetic.	7	1.33	12	3.7
They were sympathetic.	35	6.64	21	6.48
They were unsupportive.	18	3.42	19	5.86
They were supportive.	29	5.5	9	2.78
They were understanding.	17	3.23	21	6.48
They were not understanding.	26	4.93	5	1.54
They treated you bad because of your HIV status.	9	1.71	12	3.7
They treated you well.	42	7.97	19	5.86
Total	**527**	**-**	**324**	**-**

5.18 Participants who did not receive care[4]

There were 347 participants who had experienced an oral health problem and only 59 reported that they did not get care (31 in KZN and 28 in WC). They were asked to select from a list the best

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[4] For question 25, participants were allowed to choose more than one response when determining what the reasons were for not receiving care if they had experienced an oral health problem. The responses were counted and percentages were calculated by using the total number of responses as denominator.

description that would explain the reason why they did not get care. These results are summarised in Table 13. The five highest values for each province are shaed in Table 13.

In KZN, 48% of responses related to the service. 14.67% said the service was not available in their area, 14.67% said they did not know where to get the service, 13.33% said the place where the service was offered is too far and 5.33% said they had to wait too long for the service. In contrast, only 28.56% of responses in WC related to the service of which almost half were concerns about having to wait too long for the service. In KZN and WC respectively, 30.66% and 40% of responses related to the expenses tied to obtaining care, half of which were related to transport. The issues of discrimination, stigmatization and loss of confidentiality were raised in 12% of responses from KZN and 31.42% responses from WC.

Table 13: Reasons for not obtaining care

Response	**KZN**		**WC**	
	n	**%**	**n**	**%**
I was too ill to look for dental treatment.	5	6.67	0	0.00
The service was not available in my area.	11	**14.67**	2	5.71
I did not know where to get the service.	11	**14.67**	2	5.71
The place where the service is offered is too far.	10	**13.33**	2	5.71
I had no money for the transport.	13	**17.33**	7	**20.00**
I had no money to pay for service.	10	**13.33**	7	**20.00**
I had to wait too long for the service.	4	5.33	4	**11.43**
I feared what the dentist and staff might think about me being HIV positive.	1	1.33	6	**17.14**
I feared being discriminated against by the dentist and staff.	2	2.67	3	**8.57**
I feared loss of confidentiality about my HIV status.	3	4.00	0	0.00
I feared the dentist and staff might tell other people about my HIV status.	0	0.00	2	5.71
I did not feel welcome where the service was offered.	3	4.00	0	0.00
I did not have any problems.	2	2.67	0	0.00
Another reason	0	0.00%	0	0.00%
Grand total	**75**	**-**	**35**	**-**

5.19 Binary Logistic Regression

The factors influencing whether one got care or not were entered into a binary logistic regression model to compute which factors had a statistically significant effect on the dependent variable "Did you get care or not?"

The following nominal and ordinal variables were entered into the model:

- *Non-metro vs metro* area
- *Gender*
- *Marital status*
- *Educational level*
- *Moved recently*
- *Distance to service*
- *Transport*
- *Working in the past year*
- *Income Level*

The results of the model may be seen in Table 14. The following statements emerge from the model:

- participants living in a metro area were 3.647 times more likely to receive care than participants living in a non-metropolitan area ($p < 0.01$)
- long-term residents were 0.324 times less likely to receive care compared to someone who had moved recently ($p = 0.002$)
- participants living 1-5 km from the clinic were 3.371 times more likely to receive care ($p = 0.015$)
- those working part-time were 0.107 times less likely to receive care ($p = 0.011$)
- participants earning R5000 or less were 0.106 times less likely to receive care ($p = 0.048$)

Table 14: Results of Binary Logistic Regression

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1(a)	CENTER_r_or_u(1)	1.294	.351	13.573	1	.000	3.647
	Q2_Gender(1)	-.843	.370	5.200	1	.023	.430
	Q3_Mar_status			3.005	4	.557	
	Q3_Mar_status(1)	.540	.396	1.861	1	.173	1.715
	Q3_Mar_status(2)	-.083	.892	.009	1	.926	.921
	Q3_Mar_status(3)	-.175	1.158	.023	1	.880	.839
	Q3_Mar_status(4)	.740	.614	1.450	1	.229	2.095
	Q5_Edu			6.142	3	.105	
	Q5_Edu(1)	1.418	1.140	1.548	1	.213	4.130
	Q5_Edu(2)	1.150	1.137	1.023	1	.312	3.157
	Q5_Edu(3)	-1.320	1.638	.649	1	.420	.267
	Q7_Moved(1)	-1.128	.365	9.568	1	.002	.324
	Q10_Dist_to_service			6.821	3	.078	
	Q10_Dist_to_service(1)	1.215	.499	5.933	1	.015	3.371
	Q10_Dist_to_service(2)	.879	.479	3.360	1	.067	2.408
	Q10_Dist_to_service(3)	.291	.573	.258	1	.611	1.338
	Q12_TRANSPORT			.450	3	.930	
	Q12_TRANSPORT(1)	.112	.404	.076	1	.782	1.118
	Q12_TRANSPORT(2)	-19.456	11569.312	.000	1	.999	.000
	Q12_TRANSPORT(3)	.568	.847	.450	1	.502	1.764
	Q13_WORKING			8.054	3	.045	
	Q13_WORKING(1)	.055	.504	.012	1	.914	1.056
	Q13_WORKING(2)	-.677	.520	1.693	1	.193	.508
	Q13_WORKING(3)	-2.232	.877	6.476	1	.011	.107
	Q14_INCOME			4.479	5	.483	
	Q14_INCOME(1)	-.504	.508	.983	1	.322	.604
	Q14_INCOME(2)	-2.245	1.138	3.896	1	.048	.106
	Q14_INCOME(3)	-20.806	10527.403	.000	1	.998	.000
	Q14_INCOME(4)	.334	1.429	.055	1	.815	1.396
	Q14_INCOME(5)	-21.441	40192.970	.000	1	1.000	.000
	Constant	-2.344	1.186	3.905	1	.048	.096

5.20 Summary of results

This chapter has reported on the findings of this study. It summarises the demographic profile of the entire study population and highlights significant differences between the provincial cohorts where these exist. There is a high prevalence of oral health problems among the participants. A minority of the participants did not obtain the necessary oral health care when they had oral health problems. Those that did receive care were mostly treated in the public sector and a third still expressed concerns that the service was not acceptable. Of those treated in the public sector, almost half did not disclose their status and the predominant reasons for this was fear of discrimination ("*I was afraid to tell because of what they would think of me being HIV positive*") and fear of loss of confidentiality ("*I was afraid to tell them because they would tell others*"). Participants living in metropolitan areas and living close to the clinic were the most likely to get care; low income and unemployment were associated with a greater likelihood of not getting care.

CHAPTER 6: DISCUSSION

6.1 Introduction

In this chapter, the findings of this study are discussed. It commences by highlighting the socio-demography of the study population. In the subset who received care, the discussion expands on whether their status was disclosed or not and how they experienced the care and what the attitudes of the health care workers were. In those that did not receive care, the reasons why they could not obtain care are put forth. Where appropriate, reference is made to the literature in order to consider this study in the context of its similarities and differences with similar studies locally and abroad.

6.2 Limitations

The results are specific to KZN and WC and cannot be extrapolated with caution to the rest of South Africa. However, to the best of the author's knowledge, there is no other study that has compared differences in the use of oral health care services by people with HIV in South Africa and these results serve as an indication of some the important issues in this regard. The study classified participants as living in metropolitan or non-metropolitan areas. Additionally, this study did not have a control group of HIV negative people which would have enabled one to determine whether certain barriers were unique to people living with HIV.

6.3 Socio-demographic data

More females participated in both provinces. This is consistent with the HIV infection trends in South Africa as reported by Dorrington et al (2004) and internationally as reported by UNAIDS (2004). The higher prevalence of HIV/AIDS among females, especially in the 20-39 age group, increases the likelihood that more females would present at the clinics (Xu and Borders, 2003). In the WC cohort, most of the participants were from the 30-39 age group and for those living in KZN, most of the participants were from the 20-29 age group. Together, these age groups represent a substantial portion of the most economically active individuals (Swartz and Roux, 2004; Dorrington et al, 2004; Bachnann and Booysen, 2003). Morbidity from oral disease in HIV/AIDS may preclude people living with HIV from participating in the labour market and worsen the financial barrier to access care.

As expected, the sample consisted predominantly of individuals of black ethnic origin, reflecting the racial constitution of SA population. This racial group also constitutes the majority of the public health facility users (Swartz and Roux, 2004; Dorrington et al, 2004). More than half of the participants were single while a quarter were married and 10.11% where living with a partner. The literature holds the view that young, single people are vulnerable to be infected with HIV (Dorrington et al, 2004; Bachnann and Booysen, 2003) and the findings in this study reaffirm this observation. More than half of the participants had at least a secondary education. The educational level determines the level of empowerment and employability of the individual though there are no guarantees as other market factors also contribute to determining employment status and income (Bachnann and Booysen, 2003; Swartz and Roux, 2004; Dorrington et al, 2004).

A large proportion was unemployed, corresponding to the high unemployment rate for South Africa which is at about 30% (Bachnann and Booysen, 2003). This high figure may also be a reflection of the number of females in the sample who have higher unemployment figures compared to their male counterparts in South Africa (Maritz, 2002; Bachnann and Booysen, 2003). Furthermore, more than two thirds of the participants reported earning less than R1500 per month. High unemployment levels are associated with poverty (Evian, 1994; Blignaut et al, 1999) which limits the care that they can afford.

In South Africa, people who are most vulnerable to health risks are those who have inadequate or no access to health insurance such as membership of a medical aid scheme. The reason for this in many cases is affordability (Cullinan, 2006), thus many, including those living with HIV, are dependant on the public health system. More than 80% of the South African population remain uninsured (Thiede et al, 2004) and this dependence on an already overburdened public health system creates barriers to care for people living with HIV. Despite the fact that over a quarter reported that they had medical aid cover, just over a third reported that it did not cover dental treatment. According to Van der Linde (1999), nearly half of the company schemes in South Africa have a formal policy in place to deal with HIV/AIDS. The consequences of medical schemes not adequately insuring dental treatment are:

- the decreased utilisation of services by the insured in the case were there is no coverage, and/or
- the non-disclosure of status to the scheme where the self-disclosure of the insured might result in the refusal of the scheme to pay for the care.

A quarter of the respondents reported having recently moved into the area where they were currently dwelling. The socio-economic reasons for moving were work (27.62%), studying (3.64%), better housing (3.21%) and marriage (2.57%). Only 3.43% relocated for reasons directly related to health care needs. According to the binary logistic regression model, if you had not recently moved into the area where you were currently residing, you were 0.324 times less likely to get care compared to someone who had moved recently ($p = 0.002$) It appears some of the participants had moved to a different area as part of health-seeking behaviour. Labour and care-seeking migration are very common phenomena in South African - it means that residents of poorer provinces migrate to seek employment in the wealthier provinces, or those who cannot access the desired care in the poorer provinces seek this care in the wealthier provinces (Evian, 1994; Maritz, 2002; Bachnann and Booysen, 2003).

The average of duration of time the participants had known their status was 25.73 months in KZN and 42.85 months in the WC cohort. This disparity could reflect trends of better access to and quality of care in the WC. Better access to care leads to higher detection rates and earlier detection which allows participants to be retained in the health system for longer with positive spin-offs for patient morbidity and mortality. Better success with the implementation of HIV/AIDS care policies, aggressive campaigning for voluntary testing and counselling and an established ARV roll-out network are among the other reasons that may account for this longer duration of status known.

6.4 Unmet Needs

In this study, 347 participants had experienced oral health problems – this represents 79.8% of the sample and is consistent with the very high prevalence of oral health problems in people living with HIV/AIDS (Furber, 2002; Shetty, 2004). The majority reported that they were treated for the problem.

In KZN, the majority of the responses related to concerns about the service:

i) the service was not available in their area;
ii) ii) they did not know where to get the service; and
iii) iii) the place where the service was offered is too far.

In contrast, only 28.56% of responses in WC related to the service of which almost half were concerns about having to wait too long for the service. In KZN and WC respectively, 30.66% and 40% of responses related to the expenses tied to obtaining care, half of which were related to transport. The issues of discrimination, stigmatization and loss of confidentiality were also raised. These results draw a striking picture of the disparities in service delivery across the provinces (SANAC, 2007). In KZN, there is a greater need for the wider distribution of services. Patients often have to travel great distances to obtain care at centres that treat patients from a wide drainage area, creating highly stressed institutions due to the pressure to meet the demands for care. In the WC, there is an established network of services, but the demand on these services is high and the services are not equally distributed throughout the province, although the centres are more readily accessible via public transport (SANAC, 2007). KZN participants, although attending CHC's in urban areas, had travelled from rural areas. This also explains the concerns about having to travel far to services.

Obtaining care is dependent on access to information about where the care can be sought. The number of respondents who stated that they did not know where to obtain the required service was almost three times more in KZN than in the WC, most likely because services were not available in their immediate surroundings. Similar findings were reported by Shiboski et al (1999) in a study performed in the USA and emphasises that a lack of access to information is an important barrier to obtaining care.

The results of this study indicated that a very high number of the participants who experienced an oral health problem received care, and the majority of these individuals who obtained care had received service in the public sector, although the latter observation is expected due to the nature of the study sampling. The current health system performs well in rendering care to people living with HIV. This is in contrast to figures reported by authors of other studies such as Robinson and Croucher (1992) in the UK, Patton et al (2003) in the US, Shiboski et al (1999) in the USA and the HCSUS Study (2005) who reported figures of unmet needs of 87%, 65%, 43% and 20% respectively for people living with HIV. However, 17% reported that they did not receive care and it is important to investigate why these individuals are marginalised and remain undetected within the public health system. Such an endeavour underscores the aim of the DOH to provide affordable, accessible, acceptable and equitable health care for all members of society (National Consultative Health Forum, 2006; Cullinan, 2006; National Department of Health, 2007).

6.5 Accessibility

Two thirds reported that they used a taxi service to access health care centres and less than a third walked. Affordability and the distance to the health care centre determined whether the participants either walked or utilized taxi. A common complaint was the cost of taxi services. In some cases, the distance to the health care centre made use of a taxi service inevitable. The availability of public or private transport does not guarantee access to care as at times the costs prohibit travelling to a distant clinic (Cullinan, 2006) and a more extensive distribution of health care services throughout regions would addresses this problem. Although means of transport did not emerge as a factor that impeded obtaining care in the multiple logistic regression model, the amount of income did emerge as a barrier and using public transport requires money. Inaccessibility thus indirectly reflects as a barrier to obtaining care in this study. Travelling time was an important factor in obtaining care since over a third of participants took 30 to 60 minutes to reach their nearest clinic. A fifth of the participants had to travel more than an hour to the nearest clinic overall and this situation was exacerbated in KZN where a quarter of the participants travelled more than an hour to reach the health care centre.

The scenario is much better in the WC where the majority of participants took less than one hour to reach their nearest clinic service. According to the binary logistic regression model, if you lived 1-5 km from the clinic, you were 3.371 times more like to get care ($p = 0.015$). The costs of travelling, the unequal distribution of health care services and the time required to travel were barriers to obtaining care in this study for those participants that did not obtain care.

6.6 Affordability

Income impacts on the ability to obtain care as well as experience of the care obtained. Low income families often have unsatisfactory experiences with health care workers at the public health clinics and this becomes even more pronounced for people living with HIV (Harrison et al, 2003). A fifth of participants responded that they did not have enough money to pay for the transport and for the oral health care service. According to the binary logistic regression model, if you had been working part-time for the past year, you were 0.107 times less likely to get care ($p = 0.011$) and if you earned R5000 or less, you were 0.106 times less likely to get care ($p = 0.048$).

These findings are illustrated by an account of the experiences of Temba, a 40 year old male living with HIV for the past 8 years and residing in rural KZN:

> *Temba had just lost his previous job due to recurring ill health and along with it, his medical aid cover. During a time of severe illness, his whole mouth and throat started to pain severely. Unfortunately, his household had neither money nor means to take him to a clinic for care. Eventually, one of his children was sent to inform his sister. She summoned a friend of hers who was also an herbalist to visit him.*

The account of Zama further illustrates this problem.

> *Zama reported having problems with toothache but had no money for taxi fare and could not walk the long distance to the nearest clinic, so she opted to treat her toothache with a home remedy of herbs. It helped for a while, but got worse and eventually a swelling of her jaw developed. When she finally had the resources to go the hospital, she was "sick throughout her body" and her neighbours had to arrange transport for her and she was eventually operated on.*

The Development Bank of South Africa (2000), Maritz (2002) and Bhorat and Shaik (2004) report HIV positive households were worse off than HIV negative households in terms of both absolute and relative poverty levels. Schneider et al (1993) and Maritz (2002) also suggested that people living with HIV often lacked personal financial resources to purchase health care. The study conducted by Schneider et al (1993) indicates that lack of resources can severely hamper the ability of the people living with HIV to obtain care, whether it is the inability to purchase transportation to the health care centre or the inability to afford the fees charged at the health care centre.

Many studies (Furber, 2004; Mascarenhas et al, 2000; Coulter, 2000 and Heslin, 2001) have reported that income is a strong enabler to obtaining oral health care or any form of health care. Lack of income, however, is most prevalent in certain groups of our society such as the unemployed, people from poor socio-economic backgrounds, people living with HIV/AIDS and rural people and these groups have a considerable need for care (Furber, 2004; Mascarenhas et al, 2000; Coulter, 2000; and Heslin, 2001). Thus it is imperative for the government to ensure that health care is accessible and affordable to those who are dependant on the public health system.

This study also highlights the difficulty non-metropolitan people living with HIV have in obtaining care. Accessibility to care was a major reason for not obtaining care in the KZN cohort. People living in rural areas are particularly vulnerable since they have to travel long distances to the nearest town. The lack of financial resources to pay for transport and the lack of information of where to obtain health care augments the problem of accessing health care. Furthermore, physical weakness and ill health may preclude travelling long distances. In KZN, 6.67% of participants claimed they did not get care because they were too ill to seek treatment. The poor physical and mental health of people living with HIV has been demonstrated by the HCSUS (2005) to decrease the likelihood of visiting a dentist or health care worker.

According to the binary logistic regression model, if you lived in a metro area, you were 3.647 times more likely to get care than if you lived in a non-metropolitan area ($p < 0.01$). Similar results were obtained by Heckman et al (1996), Bozouich (1992) and Wismer (1992) who reported that long distances to medical facilities, lack of employment and low income made living difficult for people with HIV/AIDS in rural communities. The DOH needs to address the needs of rural communities in its strategy for acceptable, accessible, affordable and accountable health care for all.

6.7 Acceptability

Participants who had oral health problems and did obtain care were asked how they experienced the service. Of this subgroup (n = 288), close to a third reported a negative experience. Of the KZN cohort, a quarter reported a negative experience while in the WC cohort this was well over a third. One of the interviews demonstrates this scenario:

> *James was not happy with the treatment he received at the hospital dental clinic. "They were unfriendly and so disrespectful... they were not bothered and full of themselves and I am sure this was because of my status that they had noticed because of my weight loss and my patient folder." His past experiences and the experiences of a friend who also complained of being ill-treated when seeking dental care because of his status brought about this frame of mind.*

WC respondents reported that they had to "wait too long" for the services. With the demand for the services exceeding the capacity of the resources available (HST, 1995), it becomes inevitable that long waiting times will increase, adding to negative experience of health care institutions by patients. These issues ought to be addressed by the national and provincial Department of Health in the provinces in order to ensure that patients are not deterred from seeking the care that they need.

Apprehension of loss of confidentiality, stigma and discrimination were the barriers that deterred participants from seeking care. Respondents stated that they feared what the dentist and staff would think of them being HIV positive and feared being discriminated against by the dentist and staff. Ethical guidelines on confidentiality are set out in the South African Medical and Dental Council Act (No 56 of 1974) which describes a doctor's duty to keep information confidential (Hartell and Maile, 2004).

The interviews with Salomi and Jermainedepicts the experiences of discrimination in the WC:

> *Salomi is a 30 year old single mother diagnosed with HIV six years ago. She describes an incident at the dentist where she felt she was victimised due to her HIV status. "Hulle het my nie lekker behandel nie. Hulle het my soos 'n dier behandel. Hulle het op 'n manier uitgevind van my status en hulle was so onsimpatiek, maar dit was nie op daardie stadium belangrik nie, want al waaroor ek bekommer het was die pyn in my mond." When probed about what took place, she expressed her dilemma started with the administration staff as they had discovered her HIV status either from the referring doctor or in her file. They did not show any sympathy or consideration and were very impatient with her even though she had a severe toothache and could not open her mouth properly.*

In the interview with Salomi, it was evident that she felt violated by the manner in which her status had been disclosed. The sensitivity of this information is highlighted in the perceived behaviour of the health care staff. In many clinical settings, the concept of HIV exceptionalism (referring to the law-enforced practice of mandatory voluntary counselling of and consent from the patient before testing for HIV in contrast with other clinical tests which do not require these provisory steps) becomes a barrier to clinical investigation and many health care workers argue for a policy that allows more freedom to test for HIV in the clinical setting (Joska, 2008), but with the implicit message that the destigmatisation of HIV is essential to this aim. Such a movement is bound to fail if the attitudes of health care workers perpetuate discrimination.

The interview with Jermaine and Loyiso demonstrate how conditions and the attitudes of staff culminate in providing an unacceptable experience for public health care users. The participant is an insured individual who obtains regular dental care at a private dentist.

> *"The clinic was overcrowded and the staff appeared lackadaisical." At first the staff resisted treating Jermaine and Nick suspects this was a consequence of disclosing his partner's status to the receptionist. They both felt that it was their duty to disclose, especially since Jermaine had a bleeding wound. "After waiting forever, they decided to treat me but they were in a hurry to get Nick and me out of the clinic. As we left, we heard them sniggering. I felt embarrassed and was disgusted that this is a public health facility."*

Loyiso was of the opinion that it was important for the health care workers to know his status, but had the expectation that this information would handled confidentially.

> *Loyiso, a 25 year old male student from Cape Town, has been living with HIV for the past three years. A year ago, he attended a public dental clinic in Cape Town and was treated disrespectfully by the clinic staff after disclosing his status. "I came to terms with my HIV status and whenever I consult a doctor, I always disclose my HIV status. I think it is important to tell them. However, at this particular clinic, the staff members were not happy about my disclosure and asked me if I was expecting preferential treatment because of my status or whether I thought I was more special than the other patients." Loyiso was also upset that this all transpired within ear-shot of other patients. He left and went to a private dentist.*

A group interview with five participants from Cape Town explored the issue of rights to disclosure and its implications. They were unaware of or had limited knowledge of their rights regarding disclosure of HIV status. However, they did express that they hoped that the information would be handled confidentially. They agreed HIV disclosure was acceptable if it was from health care worker to health care worker provided that there was consent from the patient. This is in line with the policy of informed consent.

A cause of concern was that the patient folders that contained confidential information did not necessarily remain confidential, as it passed through many hands and personnel who had access to these files. Clearly, there was a risk that the sensitive information contained in these files may be misused.

Some participants, like Petra, however, had positive experiences.

> *Petra, a 19 year old student living in Cape Town, has known her status for a year. She said that she informed the dental clinic of her status when she attended the clinic a year ago. "They were okay; I guess I was expecting them to have an issue with my status, but they didn't. They were, in fact, very supportive and helpful and even the pulling of my tooth was not painful. They were very understanding and sympathetic of the fact that I had pain and I was HIV positive."*

According to the South African Law Commission (1998), confidentiality is not absolute and there may be situations that override public interest where there is justification for breach of confidentiality (Hartell and Maile, 2004). However, unless there is adequate justification, health care workers are ethically and legally required to keep all information confidential and seemingly this has not been the case with some of the experiences of the participants of this study where they were subjected to disclosure without consent, which constituted a breach of confidentiality (Hartell and Maile, 2004).

The results of this study indicate that discrimination of people living with HIV is still prevalent. Participants felt that they were being discriminated against because of their HIV status. This was further substantiated with the interviews with Mrs. Khetty (see later), James, Janet, and Loyiso. This has been documented by various authors such as Robinson and Croucher (1992) and Zabos (1999) where the negative attitude and approaches of the dental team acted as a barrier to attendance for dental treatment. Authors such as Hayter (1997) and Hartell and Maile (2004) emphasize that the moral duty to respect the autonomy of patients also entails protecting their confidentiality. The fear of breach of confidentiality, according to Perry (1993) and Barnes et al (1996), can discourage patients from disclosing their status or at times deter them from presenting for treatment. This can have a negative impact on prevention, treatment and destigmatisation of diseases such as HIV.

The essence of a patient's right to confidentiality is the professional duty to respect the autonomy of the patient. This is especially important for people living with HIV due to the stigmatisation associated with HIV and the harm that can be caused by unauthorized disclosure (Perry et al, 1993; Hartell and Maille, 2004). Hartell and Maille (2004) suggest that information is fundamental to disclosure and thus a person who is required to give consent must be given information about the consequences of that disclosure.

The accounts of Devan and Janet expand on this issue. The interview with Devan demonstrates the extent of the harm that may be caused by having sensitive information such as one's HIV status treated in an insensitive manner. He explained that at the time of needing dental care, he did not disclose his HIV status to the dentist or clinic staff as he thought it was not that important and feared if he divulged his status the staff will tell other people about HIV status.

> *Devan, a 25 year old male residing in Durban, was reluctant to go for treatment, fearing stigmatisation and discrimination should his immediate community discover his status if he were treated at his local clinic. "People know each other within our community and if I were to attend the clinic in my area, some staff member would probably know me and tell other people about my condition. Life would be unbearable for me if this happened. I am sure there are other young people my age group that are suffering in silence."*

Patients' prior experiences in public health institutions deter them from disclosing their status in future, as the interview with Janet demonstrates.

> *Janet, a 25 year old female, confided that she had previously been a sex worker. She was diagnosed with HIV three years ago. She visited a public dental clinic three times with complaints of the same problem. At the first clinic, she did not disclose her status because at the time she thought it was not important because she only had toothache and the dentist only did a filling on the tooth. She also expressed at that time, she had known about her status for only three months and was still coming to terms with it, sharing with me that "dit was iets wat ek nog steeds moes accept". In retrospect, even if she had known it was important to tell him, she would not have done so.*
>
> *Her second visit was at a different clinic for a swelling associated with toothache from the previously filled tooth. The staff took one look at her swollen face and, in a setting not allowing any privacy, asked her whether she was HIV-positive. She replied affirmatively, but felt ashamed to disclose in front of other people. The staff then replied that the doctor would be very busy that day and unable to see her – she was sent off with some pain tablets. "Hulle het my voor almal gevra en ek het gesê dat ek HIV positief is. Onmiddellik was hulle almal baie distant en die nursie was so onvriendelik. Ek het so sleg gevoel dat ek dadelik uitgeloop het."*
>
> *About a month later, the toothache became so severe that she approached another dental clinic to have the tooth extracted. She didn't disclose her status and the patient considered it fortunate that they did not ask. However, when probed what she would have replied if they had asked, she replied, "Ek sou nie my status erken het nie."*

The females outnumbered the males in this study which is in line with the demographics of HIV prevalence in this country (UNAIDS, 2004; Dorrington et al, 2004; Development Bank of South Africa, 2000; Thiede, 2004). Females were less likely to get care than males (p = 0.023). Shiboski et al (1999) Zabos (1999) have reported that HIV positive women under-utilise dental services and Kenagy et al (2003) indicated that a high level of vulnerable subpopulations of women and African Americans who made up the majority of their sample reported unmet needs for at least one HIV related care services.

Affordability, accessibility and acceptability were barriers to oral health care for females as reported by Greene et al (1997). These authors stated that the fear of dentists and issues more pressing than HIV infection were barriers to accessing dental care for the females in their study. In this study, many females including Mrs Khetty expressed problems to obtain oral health care. This raises the importance of recognizing the vulnerability of women, particularly those who are living with HIV, to make every effort to reduce the barriers for them to obtain necessary care.

> *Mrs Khetty related her story of when she suffered severe humiliation related to her HIV status. At the time Mrs Khetty was employed as a machinist in a leather factory. At first she became persistently ill and this resulted in her being absent from work regularly. On one occasion her absenteeism was directly linked to her painful throat and mouth. "My mouth was so painful and my gums were bleeding I even started thinking I was bleeding from inside my stomach or chest." Fearing losing her job if she was absent from work, she decided to go to work and seek care by the factory clinic where she was advised to see one of the dentists who was on the factory panel of dentists. At the dental clinic, they enquired about her HIV status to which she truthfully responded. This information was not well received by the staff and she even overheard one staff member tell another that she is "a special case" in another language. After waiting for about forty minutes, she enquired about her treatment and she was promptly given some medication and was told that she must make an appointment at the hospital if her condition still persists. "When I asked if I could get a certificate for work, the response was that I should have asked for one at first as though it was all that I had come for; it was almost as though they were implying I was being too lazy to go back to work."*

6.8 Summary

The findings of this study were both encouraging and disconcerting and emphasizes the prevailing socio-economic background and its impact on an individual's ability to obtain care, as well as the experience of public health care by users.

The majority of patients received oral health care when needed and had a good experience of the clinical setting and staff. However, there is evidence of unmet needs for oral health care among people living with HIV, as well as discrimination and breaches of confidentiality.

Marginalised groups such as women and people living in non-metropolitan regions are particularly vulnerable to unmet needs. Long distances to health care facilities, unemployment and low income levels make living with HIV/AIDS in a rural community difficult.

The DOH needs to address the needs of communities (especially in rural areas) for acceptable, accessible, affordable and accountable health care for all. Information on gender differences and the patient-to-service provider ratio in non-metropolitan regions should be utilised by the DOH to distribute and allocate resources according to need. However, an increase in access to and availability of oral health services, both in rural and urban areas, are essential. The results are similar to other studies done abroad and hopefully will assist the Department of Health in addressing the oral health needs of people living with HIV in our country.

CHAPTER 7: CONCLUSION

This study emphasises the importance of recognizing the barriers to care for people living with HIV. Barriers to care for this study group have been identified to be due to demographic, socio-economic and stigmatisation factors.

The lack of oral health services in non-metropolitan areas, lack of funds for user fees and transportation costs impede the ability of non-metropolitan persons living with HIV from accessing oral health care and this indicates the need to improve and expand oral health services for non-metropolitan people living with HIV. However, most South African families live in poverty and are dependant on the public health system. Public health care facilities are often overcrowded and not user-friendly.

The perpetuation of discrimination against people living with HIV/AIDS through the perceived behaviour and attitudes of health care workers compromises service delivery at public health institutions. Despite pervasive and ongoing resource constraints, a health care system cannot thrive if it condones disrespectful or discriminatory behaviour that undermines the dignity of those that seek care.

The fact that most participants in this study were comfortable to disclose their status is a welcome sign of the destigmatisation however, continued efforts are required to ensure health care workers are vigilant in protecting the rights of individuals and to respect and uphold their dignity by maintaining confidentiality and affording them equitable and quality care irrespective of the person's colour, creed or disposition. There is an even greater need to embrace people that are being discriminated and marginalized by society such as people living with HIV to ensure that they feel a franchised member of society who can take the initiative to be in control of their own health and, with the necessary aid from public resources and societal support, join forces to reduce the public health burden and its impact on the socio-economic milieu.

In some instances there appears to be differences between policy and practice regarding the oral health care needs of and services rendered to people living with HIV in public health facilities as there are still patients who do not obtain care and for whom the attitudes of the health care provider constitutes the major barrier to accessing that care.

Health care providers have to embrace a social responsibility to care for the most vulnerable segments of society within a culturally competent, non-judgemental and equitable health care system. The study highlighted the barriers to care existing within the current public health system relative to the provision of oral health services for people living with HIV in KZN and WC. The high prevalence of oral health problems in people living with HIV makes it imperative for the DOH to make every attempt to remove barriers to oral health care and thereby secure equitable, affordable and accessible oral health care which is acceptable for people living with HIV and accountable to our greater society.

CHAPTER 8: RECOMMENDATIONS

There is a need to expand the scope of the oral health service and suggestions include the introduction of social health insurance, the education of staff within the public health sector to abolish discrimination, the introduction of dental services as part of routine HIV clinic care, advocacy for oral health and an integrated health policy and strategy that enhances the capacity of existing HIV clinic staff to detect and effectively treat the oral manifestation of HIV. The expansion and wider distribution of the oral health service network is required to enhance access to care and it would be prudent to incorporate the training of all health care workers on the early detection, diagnosis and management of oral manifestations of HIV into such a strategy.

The expansion and wider distribution of the oral health service network is indicated to enhance access to care and it would be prudent to incorporate the training of all health care workers on the early detection and management of oral manifestations of HIV into such a strategy. Suggestions include the incorporation of a home-based care community component within the broad oral health strategy to enhance acceptability, affordability and accessibility of the service.

The provincial Department of Health may consider developing provider accountability for service delivery by fine-tuning policy and educating and enabling staff to monitor processes with regards to HIV/AIDS services to ensure that the staff is competent and equipped to carry out the obligations of their daily routines without violating the rights and dignity of those living with HIV.

The programmes and strategies of the national Department of Health ought to include co-operative arrangements across disciplines, programmes and sectors in order to address the unmet oral health care needs of people living with HIV.

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Please note: Publications, websites and map references are provided separately.

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Maps

Figures 3-7 were obtained from: Aardvark Maps. URL: http://www.aardvarkmap.net/
Last accessed 14 November 2008.

APPENDICES

Appendix 1: Table of common oral HIV lesions and management

Condition	**Management**
Oral Hairy Leukoplakia	
Bilateral whitish/grey vertical corrugations on the sides of the tongue. They cannot be wiped off.	Usually asymptomatic Effective treatment is not available Acyclovir 800mg oral 8 hour for days
Candidiasis	
Pseudo-membraneous: Creamy white or yellow patches located anywhere in the mouth, that can be easily wiped off leaving a reddish surface. Erythematous: multiple, flat red patches on mucosal surfaces like the palate, top surface of tongue and buccal mucosa. Angular Chelitis: Fissures or linear ulcers at the corners of the mouth. Typically the lesions are bilateral.	0.5% Gentian violet aqueous solution painted in the mouth 3 times daily. Nystatin suspension oral 100 000 IU /ml 2.5ml 5 times daily Nystatin oral lozenges sucked 6 hourly for ten days (1 lozenge =100 000 IU) In severe cases of if the above treatment fails: 2% Miconazole oral gel; apply twice daily for 10 days. Amphotericin B lozenges 10 mg 6 hourly for 10 days. Ketoconazole 200-400 mg oral once a day for 7 days. Fluconazole 50-100mg oral once a day for 7 days. Itraconazole 200mg oral once a day for 7 days. Dry or cracked lips can be kept moist with Vaseline, glycerine or liquid paraffin.
Herpes zoster	
Unilateral ulceration limited to the area supplied by the trigeminal nerve. It is very painful.	Acyclovir 800mg oral 5 times daily for 14 days; or Valacyclovir 1000mg oral 8 hourly for 7 days; or Famciclovir 250mg oral 8 hourly for 7 days
Aphthous Ulcers	
Simple, multiple, recurrent, well-circumscribed lesions. Whitish covering surrounded by reddish halo. Usually limited to mucosa of the soft plate, buccal mucosa, tongue and tonsillar area. Extremely painful. Recurs often.	The aims of treatment are to reduce pain, ulcer duration and increase disease-free intervals. Treatment depends on severity of ulcerations. If ulcers persist despite treatment, refer for biopsy. Although aphthous ulcers may resemble some forms of candidiasis, they will respond to steroid treatment, unlike fungal infections. *0.5% Gentian violet aqueous solution may be useful. *0.2% Chlorhexidine digluconate mouth rinse 2-4 times daily; or 1% topical povidone iodine. Topical Triamcinolone acetonide in orobase 0.1% 8 hourly. For severe ulcerations refer for treatment.

Periodontal (gum) Conditions	
Necrotising (ulcerative) Gingivitis Destruction of or more inter-dental papillae. Bleeding, ulceration, necrosis and sloughing. Tissue destruction limited to gingival tissues and does not involve alveolar bone.	Refer to oral health worker for professional scaling and local debridement with topical 1% povidone-iodine irrigation. Thorough oral hygiene is necessary: toothbrushing, flossing and 0.2% Chlorhexidine gluconate mouth rinse 2-4 times daily.
Necrotising (ulcerative) Periodontitis Advanced necrotic destruction of the periodontuim. Rapid loss of periodontal attachment and destruction or sequestration of bone.Teeth may become loose. Severe pain or bad breath may be prominent.	Amoxycillin 250mg oral 8hourly for 5 days or for penicillin-allergic patients Erythromycin 250mg oral 6 hourly before meals for 5 days and Metronidazole 200mg oral 8 hourly for 5 days Clindamycin 300mg oral 8 hourly for 7-14 days; or Clavulanic acid and Amoxycillin 375 mg oral 8 hourly for 5 days. Recall patient every 4weeks until stabilised.
Kaposi's Sarcoma	
One or more reddish or slightly bluish swellings with or without ulcerations. Predominantly seen on the gingival or palate. Kaposi's sarcoma can mimic many diseases in the early stages.	Refer for definitive diagnosis and treatment. Treatment options include • Radiotherapy for isolated oral lesions. • Intralesional injections of vinblastine. • Laser or surgical excision is sometimes useful
Parotid Enlargement and Xerostomia	
Unilateral or bilateral diffuse swelling of the parotid salivary glands. Often causes dry mouth. May be accompanied by pain. Swelling size may fluctuate.	Treat dry mouth with salivary substitutes like moisturizing, lubricating or artificial saliva containing a methylcellulose or mucin base. Glycerine may be useful. For salivary flow simulation chew sugarless gum. Topical fluoride used daily to prevent tooth decay.
Tooth Decay /Caries	
May be accompanied by pain. Swelling size may fluctuate.	Thorough oral hygiene is necessary; tooth brushing with toothpaste containing fluoride; flossing of teeth. Use topical fluoride varnish, gels or rinses. Dietary control is essential. Limit sugar and sugary foods. Fresh fruit and vegetables are preferable.

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Appendix 2: INFORMED CONSENT TO PARTICIPATE IN STUDY (English)

Dear……………………………………………….

I am a master's student in the department of Community Dentistry from the Faculty of Dentistry, University of the WC. I would like to ask you a few questions about yourself.We are doing this to see if there are ways in which we could improve accessibility for dental care. The interview will take about 15 to 20 minutes. You will be identified with a code number and your name will not appear on any form all the information you give us about yourself will be strictly confidential.

You are completely free to take part or not to take part in the study. If you decide that you do not want to be part of the study, this will not be held against you.If you would like to take part in the study, please sign the form below to allow us to proceed with the interview. If you would like to withdraw from the study at any point for any reason, please feel free to do so and no questions will be asked.

If you have any questions or queries or would like more information about the study please contact Dr M Turton on telephone number (021) 937 3151; fax (021) 931 2287; e-mail 8403619 @ uwc.ac.za or after hours on (084 7760436)
Thank you for your cooperation
Yours sincerely

Dr Mervyn Turton.

I understand what the study is about and agree to participate in the study. My consent is subject to the following:

- The results will in no way disclose the identity of the participants
- The results can be used or published for benefits in the oral health field

Name:.. Signature:..
(In block letters)
Date:...
Witness:...

Appendix 1: ENGLISH QUESTIONNAIRE FOR INTERVIEW

Please answer the questions asked and if you do not mind I will write down your responses. You may ask me for an explanation of any question if you need to and you may add comment where necessary.

Date:... Serial Number:...

1. How old are you?...years

2. Are you
   ☐ Male
   ☐ Female

3. What is your marital status?
   ☐ Single
   ☐ Married
   ☐ Separated/Divorced
   ☐ Widow/er
   ☐ Living with a partner

4. Which race group do you belong to?
   ☐ Black
   ☐ Coloured
   ☐ White
   ☐ Asian
   ☐ Other (please specify):...

5. What is your highest level of formal education?

   ☐ None
   ☐ Primary school
   ☐ High school
   ☐ Tertiary Education (college, technikon, university, etc)

6. Where is your hometown/ city?..

7. Have you moved into this area recently?

   ☐ Yes
   ☐ No

8. Have you stayed in this area for longer than 2 years?

   ☐ Yes
   ☐ No

9. Why did you move into this area?

....

10. How far do you live from the nearest dental clinic, dental hospital or dentist.

   ☐ Very close (less than 1km)
   ☐ Close (1-5km)
   ☐ Far (5-10km)
   ☐ Very far (more than 10km)

11. How long does it take you to get to the nearest dental clinic, dental hospital or dentist?

☐ Less than 15 minutes
☐ 15 minutes to 30 minutes
☐ 30 minutes to an hour
☐ More than an hour

12. How do you get there?

☐ Walking
☐ Taxi
☐ Bus
☐ Private vehicle

13. In the past year were you working

☐ Not working at all
☐ Working full-time
☐ Working part-time (all the time/permanently)
☐ Working part-time (some of the time/seasonal)

14. What is your monthly income?

☐ Less than R1000
☐ Less than R3000
☐ Less than R5000
☐ Less than R10000
☐ Less than R15000
☐ R15000 or more

15. Do you have medical aid?

☐ Yes

☐ No

16. If yes, does your medical aid pay for all your dental visits?

☐ Yes

☐ No

17. How long have you known your HIV positive status?

Years ....

Months ....

18. Since you were diagnosed as HIV positive have you needed mouth care?

☐ Yes

☐ No

If the answer is no the interview ends. The participant will be thanked for their participation and given a letter of and a small gift as a token of appreciation.
If yes the interview proceeds with question 19.

19. If yes, did you receive help for the mouth problem?

☐ Yes

☐ No

If the answer is yes, the interview proceeds to question 20

If the answer is no, the interview proceeds to question 25.

20. Where did you receive the care?

☐ Private Dentist
☐ Dental Clinic
☐ Hospital Dentist
☐ Hospital Doctor
☐ Medical Doctor
☐ Pharmacy
☐ Traditional Healer
☐ Other (please explain):..

21. Did the staff or health care workers where you were getting treatment know that you are HIV positive?

☐ No, they did not ask so I did not tell them.
☐ No, I did not tell them even though they asked
☐ Yes, they asked me and I told them
☐ Yes, I told them even though they did not ask
☐ Yes, the doctor who sent me told them.
☐ Yes, they found out in some other way (please explain):
....

If the answer is yes, leave out question 22, the interview proceeds to question 23 and ends at question 24. If the answer is no, the interview proceeds to question 22 and ends there.

22. If no, why did you not tell them?

☐ I was afraid to tell them because of what they would think of me being HIV positive.
☐ I was afraid to tell them because they would tell others.
☐ I did not tell them because they did not ask.
☐ I did not think it was important to tell them that I was HIV positive.
☐ I did not see a reason to tell them about my HIV status because
☐ I was just receiving dental treatment.
☐ I was in so much pain that I did not consider telling them about my HIV positive condition.
☐ I was afraid they would refuse to treat if they knew I was HIV positive

23. If your answer is yes, how did they find out?

a) I told them because they asked me about my HIV status. ☐
   I told them even though they did not ask about my HIV status. ☐

b) I told them because I thought it was important for them to know. ☐
   I told them even though I did not think it was important for them to know. ☐

c) My relative/s (father, mother, brother, sister, cousin) advised me to tell them so I told them told them. ☐
   My relative/s Father, mother, brother, sister, cousin) told them. ☐

d) My partner (wife/husband/boyfriend/girlfriend) advised me to tell them so I told them. ☐
   My partner (wife/husband/boyfriend/girlfriend) told them. ☐

e) The doctor that sent me to them advised me to tell them so I told them. ☐
   The doctor that sent me to them told them. ☐

24. In the case where they knew you were HIV positive what do you feel their attitude was like about the fact that you were HIV positive?
Please comment where you feel like it.

a) They made you feel unwelcome. ☐
   They made you feel welcome. ☐
   Comment:..
   ....

b) They seemed unhappy to treat you. ☐
   They seemed happy to treat you. ☐
   Comment:..
   ....

c) They were very worried about being infected by you. ☐

They did not show concern about being infected by you. ☐

Comment:..

d) The treatment was rushed. ☐

Their treatment was not rushed. ☐

Comment:..

e) They were impatient. ☐

They were patient. ☐

Comment:..

f) They were unhelpful. ☐

They were helpful. ☐

Comment:..

g) They were unsympathetic. ☐

They were sympathetic. ☐

Comment:..

h) They were unsupportive. ☐

They were supportive. ☐

Comment:..

i) They were understanding. ☐

They were not understanding. ☐

Comment:..

j) They treated you bad because of your HIV status. ☐

They treated you well. ☐

Comment:..

25. What was the reason for you not receiving dental treatment since you were diagnosed as HIV positive?

☐ I was too ill to look for dental treatment
☐ The service was not available in my area
☐ I did not know where to get the service
☐ The place where the service is offered is too far
☐ I had no money for the transport
☐ I had no money to pay for the service
☐ I had to wait too long for the service
☐ I feared what the dentist and staff might think about me being HIV positive.
☐ I feared being discriminated against by the dentist and staff.
☐ I feared loss of confidentiality about my HIV status.
☐ I feared the dentist and staff might tell other people about my HIV status.
☐ I did not feel welcome where the service was offered.
☐ I did not have any problems.
☐ Another reason (please explain):..
....

Thank you for your participation.

Appendix 3: INFORMED CONSENT (Afrikaans)

Geagte……………………………………….

Ek is ‘n messter's student in die department Gemeenskaps tandheelkunde aan die Fakulteit Tandheelkunde, Universiteit van die Weskaap. Ek wil u ‘n paar vrae omtrent uself vra. Ons doen dit om te sien of daar wyses is waarop ons toegabnklikheid van dienste kan verbeter. Die onderhoud sal ongeveer 15 tot 10 minute duur. U sal geïdentifiseer word deur middel van ‘n kode en u naam sal op geen vorm verskyn nie en die inligting wat u omtrent uself verskaf sal strent vertroulik hanteer word.

U deelname of die feit dat u nie deelneem nie hang uitsluitlik van u af. Indien u Indien u besluit om nie deel teneem aan die studie nie, sal dit nie teen u gehou word nie. Indien u wil deelneem aan die studie teken die vorm hieronder om ons toestemming te verleen om aan te gaan met die onderhoud. Indien u op enige stadium van onttrek aan die studie vir welke rede ookal, voel vry om so te doen en geen vrae sal gevra word nie.

Indien u enige vrae of navrae het en meer inligting verlang sakkel asseblief Dr M Turton by telefoon nommer (021) 937 3151; faks (021) 931 2287; e-pos 8403619 @ uwc.ac.za of na ure by (084 7760436).
Dankie vir u samewerking
Die uwe

Dr Mervyn Turton.

Ek verstaan wat die studie behels en gee my toestemming om daaraan deel te neem. My toestemming is onderhewig aan die volgende:

- Die resultate sal in geen opsig die deelnemers se identiteit bekend maak nie
- Die resultate kan gebruik en gepubliseer word tot voordeel in die mondgesondheids omgewing.

Naam:..   Handtekening:...
Datum:..
GetuieWitness:...

Appendix 4: INFORMED CONSENT (Zulu)

Igama lami ngingu Mervyn Turton, ngivela kuphiko olufundisa ngamazinyo eNyuvesi yase Ntshonakoloni, lolucwaningo elukuthola ukuthi yiziphi izinkinga ezikhona kubantu abaphila nesandulela ngculazi ekutholeni usizo lokunakekelwa kwamazinyo. Loluphenyo luzothatha imizuzu emibalwa yesikhathi sakho uma ungenankinga ukuba yingxenye yalolu vivinyo. Ngingathokoza kakhulu uma ungasayina ifomu lokungivumela ukuba ngiqhubeke nophenyo.Ngiyabonga kakhulu. Ngingumfundi ovelele kuphiko lwamazinyo olusebenza ngabantu bendawo, kuphiko olusebenza ngamazinyo kwiNyunivesi yase ntshona koloni. Ngithanda ukubuza imibuzo emibalwa ngawe.Senza lokhu ukubona uma kungakhona izindlela esikhathuthukisa ukutholakala kokunakekelwa kwamazinyo. Loluphenyo luzothatha imizuzu eyishumi nanhlanu kuya kimizuzu engamashumi amabili (15-20 minutes), uzokwaziwa ngenombolo azonikwa yona. Igama lakho ngeke livele kwifomu, yonke imininingwane ngawe izogcinwa iyimfihlo.

Ukhululekile ukuba ingxenye yaloluphenyo, uma futhi ungeke ukwazi wamukelekile. Uma ubona ukuthi ngeke ukwazi ukuba ukuba yingxenye yaloluphenyo, likho ngeke kwenze ukuba ubanjelwe amagqubu. Uma ufuna ukuba yingxenye, sicela usayine ifomu ngezansi elisivumela ukuba siqhubeka nophenyo.Uma ungafuna ukuhoxa ngezizathu ezithile noma inini, wamukelekile ukwenza lokho, futhi ayikho imibuzo ezobuzwa. Uma unemibuzo noma ufuna ulwazi olungaphezulu ngaloluphando sicela ushayele noma uthinte uDokotela uM.S. Turton kulenombolo (021) 9373151, noma umufekisele kulenombolo (021) 9312287, e-mail 8403619 @ ucw.c.o.za emva kesikhathi ku (0827760436).

Ngiyabonga ngokungibekezelela. Yimi ozithobayo
Dr Mervyn Turton

Ngiyazi ukuthi loluphenyo lungani futhi ngiyavuma ukuba womunye abangenele loluphenyo. Imvume yami incike kokulandelayoimiphumela ngeke ize imuveze umnikazi. Imiphumela ingasetshenziswa noma ishicilelwe ukuze abasiza ngokunakekelwa kamazinyo

Igama:.. Sayina:..
(ngamagama amakhulu)
Usuku:..
Ufakazi:..

Appendix 5: INFORMED CONSENT (Xhosa)

Igama lami ndingu Mervyn Turton, ndivela kwisebe elifundisa ngamazinyo kwiDyunivesiti yeNtshona koloni. Olu luphando lokufumana ukuba ziziphi iingxaki ezikhona kubantu abaphila nesandulela sengculaza ekufumaneni uncedo lokukhathalelwa kwamazinyo wabo. Olu dliwano-ndlebe luzakuthatha imizuzu embalwa yexesha lakho ukuba awunangxaki yokuba yinxalenye yalo. Ndakuyivuyela kakhulu ukuba ungasayina ifom endivumela ukuba ndingaqhubeka nophando.Ndiyabulela kakhulu. Ndingumfundi ophezulu kwicandelo lwamazinyo olusebenza ngabantu basekuhlaleni (community dentistry), kwisebe elisebenza ngamazinyo kwiDyunivesiti yase Ntshona Koloni. Ndingathanda ukubuza imibuzo embalwa ngawe.Senza oku ukufumana ukuba zingakhona na iindlela ezingaphucula ukufumana uncedo ngokukhathalelwa kwamazinyo. Olu dliwano-ndlebe luzokuthatha imizuzu elishumi nantlanu ukuya kwimizuzu engamashumi amabini(15-20 minutes), uzakwaziwa ngenombolo ozakunikwa yona eyimfihlo. Igama lakho alingeke livele kwifom, yonke into ebhalwe ngawe izakugcinwa iyimfihlo.

Ukhululekile ukuba yinxalenye yoluphando, ukuba awunakukwazi noko kwamkelekile. Ukuba ubona ukuba angeke ukwazi ukuba yinxalenye yoluphando awunakuthathelwa manyathelo. Ukuba ufuna ukuba yinxalenye, sicela usayine ifom engezantsi esivumela ukuba siqhubeka nophando.Ukuba ungafuna ukurhoxa ngezizathu ezithile nokuba kunini, wamkelekile ukwenza oko, futhi ayikho imibuzo ezakubuzwa.

Ukuba unemibuzo nokuba ufuna ulwazi olungaphezulu ngoluphando sicela utsalele umxeba uGqirha uM.S. Turton kulenombolo (021) 9373151, okanye umfeksele kulenombolo (021) 9312287, e-mail 8403619 @ uwc.ac..za, emva kwexesha lomsebenzi ku (0827760436).

Ndibulela intsebenziswano yakho. Ndim ozithobileyo

Dr Mervyn Turton

Ndiyazi ukuba olu phando lungantoni kwaye ndiyavuma ukuba ngomnye wabangenela oluphando

- Iziphumo zophando azinakuveza igama lam (umnikazi).
- Iziphumo ziyakusetyenziselwa okanye zishicelelwe ukunceda abanceda ngokukhathalelwa kamazinyo

Igama:... Sayina:...

Usuku:...

Ingqina:...

Appendix 6: INTERVIEWS IN KWAZULU NATAL

Interviews were performed with eleven random participants.

KZN

Solanus

Solanus is a 28 year old male residing in KZN. He has been HIV positive for the past four years. It emerged that he had to travel quite a distance to the nearest town to obtain treatment if he perceived his condition was serious. Generally he treats himself at home with home remedies. Solanus said that fortunately for him he has not experienced any oral health problems since his diagnosis with HIV. However when asked about where he will obtain care should he have an oral health problem he replied that he would have to travel to the same town where he gets attended to for his other medical conditions. This would mean Solanus would have to travel this distance to access oral health care as well, should he not be able to success fully treat himself at home with home remedies.

Temba

Temba is a 40 year old male residing in Esigodini in rural KZN and has been living with HIV for the past eight years. He spends most of his time on the road as he is currently employed as a long distance truck driver. Temba indicated that he has had oral health problems three times since he was diagnosed with HIV. The first instance led to an uneventful visit to a private dentist. The second instance, however, was problematic: he had just lost his previous job due to recurring ill health and along with it, his medical aid cover. During a time of severe illness, his whole mouth and throat started to pain severely. Unfortunately, his household had neither money nor means to take him to a clinic for care. He indicated that the pain was so severe that in his weakness, he attempted to walk to the nearest road where he could possibly find a lift to the clinic, but due to his lack of strength he had to turn back to his home. Eventually, one of his children was sent to inform his sister who lived on the other side of valley. She summoned a friend of hers who was also an herbalist to visit him. The traditional medication that he took helped him with the oral health problems and also with regaining his strength. Temba was eventually taken by his sister to the clinic and the doctors started him on anti-retroviral therapy. He was also given medication for his oral health problems and recovered to such an extent that he could find another job.

Ntando

Ntando is a 28 year old male student from Nongoma and has been living with HIV for the past four years. Ntando indicated that when he had oral health problems in the form of oral ulcers and bleeding gums, he was treated by his medical practitioner and he did not realise the need to consult a dentist. He indicated that the treatment received from the medical practitioner was rushed, possibly due to his doctor being very busy on that day. His general experience is that his doctor is sympathetic and considerate.

Devan

Devan is a 25 year old male residing in Durban. He is HIV positive for three years. He was initially reluctant to be interviewed, but consented when he was informed it would be anonymous and confidential. It emerged that he was from another part of town and had travelled quite a distance to the other side of town to get treatment, fearing stigmatisation and discrimination should his immediate community discover his status if he were treated at his local clinic. "People know each other within our community and if I were to attend the clinic in my area, some staff member would probably know me and tell other people about my condition. Life would be unbearable for me if this happened. I am sure there are other young people my age group that are suffering in silence." He explained that at the time of needing dental care, he did not disclose his HIV status to the dentist or clinic staff as he thought it was not that important and feared if he divulged his status the staff will tell other people about his HIV status.

Zama

Zama is a 30 year old mother of two children from rural KZN who is living with HIV for four years. She is dependent on her husband who sends her money – he works in Gauteng. Zama states that when there is no money in the household, they have to walk to seek health care or try to treat themselves as best as they can at home. Zama expressed to me that once she had problems with toothache but had no money for taxi fare and could not walk the long distance to the nearest clinic, so she opted to treat her toothache with a home remedy of herbs. It helped a bit for a while, but got worse and eventually swelling of her jaw developed. When she finally had the resources to go the hospital, she was sick throughout her body and her neighbours had to arrange transport for her and she was eventually operated on.

James

James is a 33 year old male from Durban who has had HIV for five years. He was not happy with the treatment he received at the hospital dental clinic.

> “They were unfriendly and so disrespectful... they were not bothered and full of themselves and I am sure this was because of my status that they had noticed because of my weight loss and my patient folder.”

On further enquiry, James admitted that now that he has recovered, he will be reluctant to disclose his status when he seeks dental care in future. His past experiences and the experiences of a friend who also complained of being ill-treated when seeking dental care because of his status brought about this frame of mind.

Mrs Khetty

Mrs Khetty related her story of when she suffered severe humiliation related to her HIV status. At the time Mrs Khetty was employed as a machinist in a leather factory. At first she became persistently ill and this resulted in her being absent from work regularly.

On one occasion her absenteeism was directly linked to her painful throat and mouth.

> “…my mouth was so painful and my gums were bleeding I even started thinking I was bleeding from inside my stomach or chest...my throat was so sore I could not eat or swallow.

Because of her fear of losing her job if she was absent from work, she decided to go to work and seek care by the factory clinic where she was advised to see one of the dentists who was on the factory panel of dentists. At the dental clinic, they enquired about her HIV status to which she truthfully responded. This information was not well received by the staff and she even overheard one staff member tell another that she is a special case in another language. After waiting for about forty minutes, she enquired about her treatment she was promptly given some medication and was told that she must make an appointment at the hospital if her condition still persists. Mrs Khetty expressed that she was disappointed at the services rendered and she felt her disclosure of her HIV status brought about a very cold and unsupportive response from the staff.

> "…when I enquired if I could get a certificate for work the response was that I should have asked for one at first as though that is all I had come for; it was almost as though they were implying I was being to lazy too go back to work."

Appendix 7: INTERVIEWS IN WESTERN CAPE

Salomi

Salomi is a 30 year old single mother who was diagnosed with HIV six years ago. She is thankful that her only child of six has not contracted the disease.

> "Alhoewel my lewe so swaar is met die Vigs en geen probleme met geen werk, dank ek die Here dat my kind gesond is en nie aangeval is met my siekte nie."

She describes an incident at the dentist where she felt she was victimised due to her HIV status.

> "Hulle het my nie lekker behandel nie. Hulle het my soos 'n dier behandel."

When probed about what took place, she expressed her dilemma started with the administration staff as they had somehow discovered about her HIV status either from the referring doctor or where it was written in her file. They did not show any sympathy or consideration and were very impatient with her even though she had a severe toothache and couldn't open her mouth properly. At the time, her throat was also sore precluding her from swallowing and she had generalised body aches that caused difficulty in walking.

> "Hulle het op 'n manier uitgevind van my status en hulle was so onsimpatiek, maar dit was nie vir op daardie stadium belangrik nie, want al waaroor ek bekommer het was die pyn in my mond."

Janet

Janet, a 25 year old female, confided that she had previously been a sex worker. She was diagnosed with HIV three years ago. She visited a public dental clinic three times with complaints of the same problem. At the first clinic, she did not disclose her status because at the time she thought it was not important because she only had toothache and the dentist only did a filling on the tooth. She also expressed at that time, she had known about her status for only three months and was still coming to terms with it, sharing with me that "dit was iets wat ek nog steeds moes *accept*". In retrospect, even if she had known it was important to tell him, she would not have done so.

Her second visit was at a different clinic for a swelling associated with toothache from the previously filled tooth. The staff took one look at her swollen face and in a setting not allowing any privacy asked her whether she was HIV-positive. She replied affirmatively, but felt ashamed to disclose in front of other people. The staff then replied that the doctor would be very busy that day and unable to see her – she was sent off with some pain tablets.

> "Hulle het my voor almal gevra en ek het gese dat ek HIV positief is. Onmiddellik was hulle almal baie *distant* en die *nursie* was so onvriendelik. Ek het so sleg gevoel dat ek dadelik uitgeloop het."

About a month later, the toothache became so severe that she approached another dental clinic to have the tooth extracted. She didn't disclose her status and the patient considered it fortunate that they did not asked. However, when probed what she would have replied if they had asked, she replied, "Ek sou nie my status erken het nie."

Noxolo

Noxolo is an unemployed 23 year old female who moved to Philippi, Cape Town, to seek work. She found out about her status a year ago while living in Idutywa in the Eastern Cape. At that time, she also suffered from severe weight loss, a sore throat and bleeding gums to the point that she couldn't eat. When she complained to a medical doctor about the problem, he gave her medication and referred her to the dental clinic in the hospital where she was being treated. When she went to the clinic, she did not feel welcome. They looked at her curiously and immediately asked her about her status and whether she had been evaluated by a medical doctor before attending the clinic. She replied that she had received treatment and they told her to take medication and go home.

> "I felt very disappointed in the service as I knew of a friend with a problem of bleeding gums that was treated by the dentist at the same clinic and not just given medication to swallow."

She says she feels it was because of her status that they chose not to treat her further.

Jermaine

Jermaine is 34 year old male who is originally from Oudtshoorn but is presently living with his partner, Nick, in Cape Town. The couple have been living with HIV for the past five years. They have regular dental care at a private dentist whom they know very well. They both express regrets about having attended a public dental care facility in a rural town in the Western-Cape after Jermaine had an accident while mountain biking, fracturing two teeth and lacerating his lip. They were advised that the nearest source of care would be the dentist in the nearby town. After travelling about 50km, they arrived at the clinic and were appalled by the prevailing conditions.

The clinic was overcrowded and the staff appeared lackadaisical. At first the staff resisted treating Jermaine and Nick suspects this was a consequence of disclosing his partner's status to the receptionist. They both felt that it was their duty to disclose, especially since Jermaine had a bleeding wound.

> "After waiting forever, they decided to treat me and their attitude implied that I was being a nuisance. They were in a hurry to get Nick and me out of the clinic. As we left, we heard them sniggering. I felt embarrassed and was disgusted that this is a public health facility."

Loyiso

Loyiso is 25 year old male student from Cape Town living with HIV for the past three years. A year ago, he attended a public dental clinic in Cape Town and was made to feel very unwelcome and disrespected by the way the clinic staff treated him after disclosing his status.

> "I came to terms with my HIV status and whenever I consult a doctor, I always tell them. I think it is important to tell them. However, at this particular clinic, the staff members were not happy about my disclosure and asked me if I was expecting preferential treatment because of my status or whether I thought I was more special than the other patients. They also rudely reminded that they did not ask me about my status and that I was being unnecessary and forward. I later had to leave because the telling-off just did not seem to come to an end and accusing me of not following my traditions [i.e. the cultural tradition of respecting one's elders]."

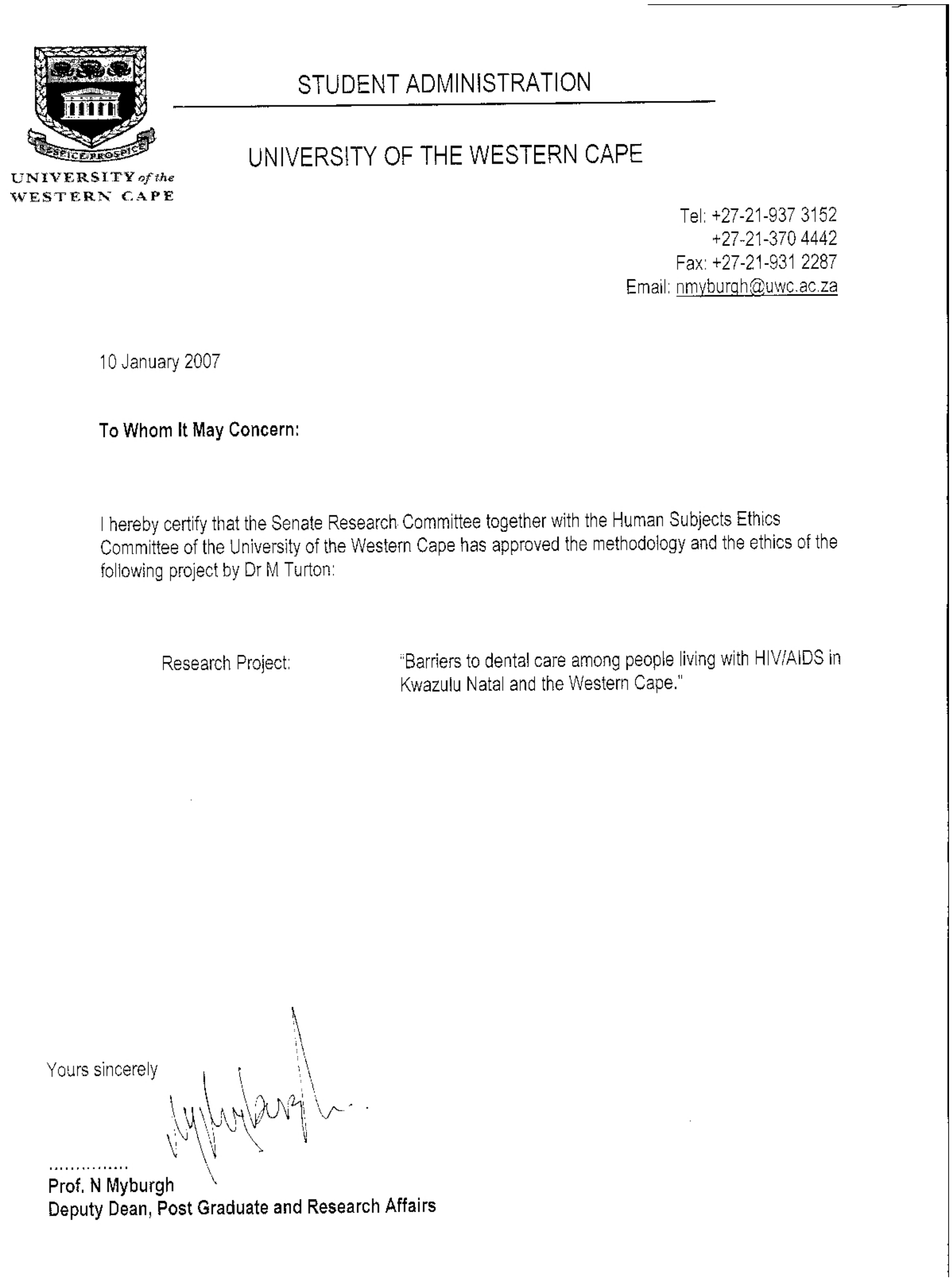
Loyiso was also upset that this all transpired within ear-shot of other patients; he left and went to a private dentist.

Petra

Petra, a 19 year old student living in Cape Town, has known her status for a year. She said that she informed the dental clinic of her status when she attended the clinic a year ago. The staff was helpful and friendly and she did not have any problems with the service. She was impressed with their understanding and sympathy not only of her dental pain, but also of her HIV status. This has contributed to her coming to terms with her HIV status.

> "They were okay; I guess I was expecting them to have an issue with my status, but they didn't. They were, in fact, very supportive and helpful and even the pulling of my tooth was not painful. They were very understanding and sympathetic of the fact that I had pain and I was HIV positive."

Appendix 8: APPROVAL OF RESEARCH STUDY BY UWC HUMAN SUBJECTS ETHICS COMMITEE



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10 January 2007

To Whom It May Concern:

I hereby certify that the Senate Research Committee together with the Human Subjects Ethics Committee of the University of the Western Cape has approved the methodology and the ethics of the following project by Dr M Turton:

Research Project:	"Barriers to dental care among people living with HIV/AIDS in Kwazulu Natal and the Western Cape."

Yours sincerely

....
Prof. N Myburgh
Deputy Dean, Post Graduate and Research Affairs