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**THE PREVALENCE OF ORAL SYMPTOMS AND PERCEIVED NEEDS
OF HIV POSITIVE PERSONS IN CAPE TOWN, SOUTH AFRICA**

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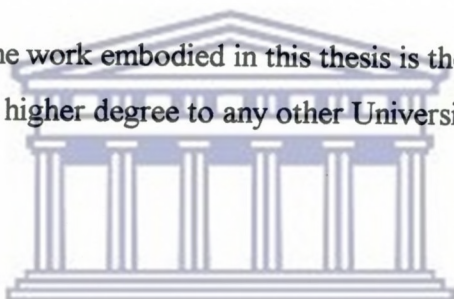
**Submitted as part fulfilment of the requirement
for the Masters Degree in Medical Science (Health Promotion)**

Submitted: May 1996

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DECLARATION

I hereby certify that the work embodied in this thesis is the result of original research and has not been submitted for a higher degree to any other University or institution.



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(Signed)

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DEDICATION

This thesis is dedicated to my mother Ruth Olga Jeftha née Gordon. She is always there to love, support and encourage despite her frailty. My eternal love.



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SUMMARY

The Human Immunodeficient Virus (HIV) is escalating in South Africa at an alarming rate. The impact of HIV today and in the future could have grave consequences for the South African population as it affects adults in their most productive years. To ease costs on the health system, health workers should be familiar with HIV patients needs in general, and specifically in areas such as oral disease which can contribute to the wellness or ill health of the patient. This could facilitate more appropriate and cost effective care of HIV patients.

World-wide reports indicate that the HIV virus is more prevalent in females than males. Women are also experiencing greater virulence of HIV and therefore greater severity of the disease. This research assessed whether there were differences in the prevalence and severity of oral symptoms of HIV positive men and women. Oral health practices were also examined. As oral disease is very prevalent in HIV positive persons and has been a neglected area for research and program development, it was included in this study.

This study also aimed to assess the perceived needs of patients affected by HIV. Such a study presents HIV positive patients an opportunity to participate in a process which allows patients to voice their needs and problems, as well as be involved in setting priorities. The study sought to assess whether needs differed according to the patients gender, age and symptom levels. A needs questionnaire with five domains which included medical and oral needs, social, economic, psychological and informational domains of needs was developed. The measure also included a section on demographics and oral health questions, and was administered as a structured interview.

The sample consisted of 338 HIV positive males and females residing in Cape Town and its environs and attending the Out Patients' Departments of three major provincial hospitals, as well as two community clinics during May to November of 1995.

RESULTS

Oral Section

Prevalence of oral symptoms for females and males were similar with only one symptom showing a statistically significant difference between males and females. More males (41%) than females reported having calculus (26%). A high proportion of both males and females reported having experienced at least some oral symptoms since diagnosis. The most common symptoms were bleeding gums, decayed teeth, candidiasis oro-facial pain and plaque which had been experienced by at least 40% of patients. The proportion of males (n=128) reporting they were currently having problems with their mouth was 72%. The corresponding figure for females (n=210) was 66% and for the overall sample it was 68%. Chi-square analysis showed the percentage currently experiencing oral problems did not differ significantly between gender groups ($p>0.05$).

In relation to oral health practices, only about 36% of patients had received a scaling and polishing or oral education and instruction. Twenty-four per cent had received fillings and 64% had had extractions. Forty-one per cent of the patients maintained that they brushed their teeth more than once per day.

The severity ratings were examined for each of the 14 symptoms. Significant differences emerged on one symptom. Males were more likely to report severely decayed teeth and less likely to report mild decay than females ($p=0.029$).

Needs Section

Factor analysis was used to define the domains of need. Six domains or factors were identified, namely, socio-economic, informational, psychological, social support, oral and medical and physical needs. At least 25% of the sample reported moderate or high need on all twenty-eight items in the different domains. At least half the sample reported moderate or high need on fifteen items. Of the ten items for which the highest proportion of the sample rated a need, six were in the informational domain, with the highest ranked items being the need for information about disability grants and oral disease. All of the six items in the informational factor were among the

top ten needs. Of the remaining items in the top ten, one fell within the medical-oral domain (help in coping with stress); one in the socio-economical (help with a job at home); one in the psychological (help in coping with fears about being left alone) and one in the support domain (need for support from friends).

The analysis results which compared mean scores on each factor for patients grouped according to gender, age and being symptomatic or not yielded the following information. The factor scores across all six factors were fairly similar for males and females. However, females scored significantly higher on the informational domain. The result for Factor 1: socio-economic, was just beyond significance. Factor scores for the symptomatic and asymptomatic groups were significantly different on factors 1, 2, 3 and 5, with the symptomatic group showing higher need in those domains, namely socio-economic, informational, psychological and support domains. There were no significant differences between age groups.

CONCLUSION

Most studies about HIV/AIDS patients focus on the advance stages of the disease. This study reports findings for the early stages as the focus is only on HIV patients and not AIDS patients. This study gives an indication that HIV positive patients need selective care, education and information across a broad spectrum of issues. Programs for HIV positive persons should address issues concerning information, early detection of oral disease symptoms, education about oral disease, distinguishing between a healthy and a diseased mouth and how to cope with other general symptoms of the disease. As patients live a number of years after being diagnosed, there is a need to enhance quality of life and focus on the maintenance of optimal functioning.

CHAPTER 1:

BACKGROUND AND AIMS OF THE STUDY

1.1 The burden of illness of HIV in South Africa

1.1.1 Prevalence of HIV

The number of persons infected with HIV worldwide is estimated at almost 14 million, with a predicted estimate of 40 million infected by the end of this decade.¹ The predicted escalation of HIV in South Africa is clearly evident.² Between 1.2 million and 1.8 million people are already infected with HIV and about 12,000-15,000 people have AIDS.³ There are about 800 new infections every day and it is estimated that about 250,000 South Africans will be sick and dying from AIDS within the next four years.⁴ Policy decisions which originated in the apartheid era such as migrant labour, single hostel dwelling and Bantu education as well as cultural practices such as sexual rites associated with important life events, circumcision practices and beliefs that disease and other afflictions can be cured by passing them to others have had ample time and opportunity to accelerate and compound the complexity of the disease and its spread.^{5, 6, 7}

The major pool of HIV infection is in the urban black community which constitutes 69 per cent of all HIV infected individuals in the country.⁸ The next largest group, the rural black population, constitutes 20 per cent of the total HIV positive population.⁸ Nine seroprevalence surveys have been conducted in South Africa by the Department of National Health and Population Development (DNHPD).⁹ Five were done nationally and the other four conducted in rural areas of Northern Natal and Kwa-Zulu. In the fifth national survey, 18,630 specimens of blood from antenatal clinic attenders were considered eligible for estimating HIV prevalence. Specimens representative of all nine provinces were received, although some areas within provinces were not well represented.⁹ The results of these anonymous, annual national HIV surveys among women show how rapidly the HIV epidemic is expanding.

Data concerning HIV test results from private laboratories, the National Institute of Virology and virology departments of various universities demonstrates that there is a doubling of infections

every 13-15 months in the heterosexual population.¹⁰ Infection is more common among young people between the ages of 15 and 30, women and the mobile, working population.¹⁰ More recent data estimate the doubling time to be between 11 and 13 months.³

Countrywide prevalence was found to be 8% in 1994 as opposed to 5% in 1993.³ The results of the rural prevalence data ranged between 1% and 14% with the highest prevalence of HIV infection in the rural part of Northern Natal/KwaZulu. The lowest was recorded in the Cape, namely, 1%.³ Data from sentinel surveillance surveys complement the national surveys and give vital indications of geographical variations and local trends. Results of some of these surveys, which were conducted in the Johannesburg and Cape environs, indicate that 7% of urban women (n = 1,377) were infected as opposed to 3% of rural women (n = 1,404).¹¹

The virus is spreading rapidly among young people between the ages of fifteen and thirty years.³ Surveys in rural Kwa-Zulu Natal demonstrate a rise from 2% in 1990 to 6% in 1992 in this age group.¹¹ Younger women are acquiring the infection at least five to ten years earlier than men and proportionally more young women in their teens and early twenties are becoming infected than women in any other age group.^{1, 11, 12, 13, 14, 15, 16} Cape Towns' local Health Minister, Mr. Ebrahim Rasool, estimated on the basis of the results of sentinel surveys, that one in ten sexually active women was HIV positive in the black suburbs of Cape Town.¹⁷ The level of HIV-infection among pregnant adolescents was 7%, rising to 9% and 8% in the 20-24 and 26-29 year age groups respectively. Furthermore, about four out of ten babies born in South Africa are being delivered by teenage mothers.⁹

Results from the national surveys also indicate that more females are infected than males.^{11, 18, 19} These surveys showed prevalence rates for women ranged from 2% to 6% and for men between 0.4% and 2%. The highest prevalence for HIV infection was found in women of child-bearing ages (15-44 years) and this ranged from 2% to 6% – depending on the geographical area.¹⁹ Studies world-wide also indicate that females are being infected at a greater rate than males.^{8, 14, 20, 21, 22, 23} In South Africa five times as many females than males are being affected in the 15-19 year age group.¹⁰

Women have increased susceptibility to HIV infection.²⁴ Reasons which are suggested basically fall into two categories: biological and sociological.²⁴ One biological explanation proposes that menstrual blood is a potential growth medium for HIV and raises the PH to neutral range. Semen also neutralises the PH of the vagina for 30 minutes to several hours and the HIV deposited in the vagina remain viable for a longer time.²⁴ Sociological explanations suggest that HIV is more effectively transmitted from males to females because of the passive role that women are expected to and do take in sexual matters. For example, it is very difficult for women to insist on condom use by their male partners.²⁵ Poor socio-economic conditions, unequal gender relations and lack of access to health care and education all help to increase the vulnerability of women to HIV infection.²⁶ Lack of access to health care and poor education have been implicated in the possible reasons for the higher prevalence of untreated ulcerative sexually transmitted diseases in women.²⁷

It is also reported that women who are infected show a greater degree of HIV virulence and a more rapid progression to AIDS, than men. Several studies have suggested that women have a lower median survival than men and it is not known whether pregnancy or co-factors such as genito-urinary tract infections, sexually transmitted disease, age, mode of acquisition of HIV infection and the biologic properties of HIV variants increase the rate of progression to AIDS.^{8, 14, 20, 21, 22, 23}

While the above data provide valuable information on the magnitude of HIV infection, the prevalence of HIV in South Africa is not fully understood since data from the existing surveys represent a simple count of positive cases derived from sera in laboratories and were not intended to provide information of any greater significance than passive surveillance of trend.¹¹ There may well be many undetected cases in the community, and the information supplied is therefore limited.

1.1.2 Impact on society and health care

The impact of HIV to-day and in the future could have grave consequences for the South African population, as it affects adults in their most productive years and leaves many children orphaned.²⁸ These factors could contribute to a society consisting mainly of the very young and old, and one where persons need a lot of treatment who normally would not have needed it. The burden of the disease on the health system is enormous as more patients attend hospitals, clinics and need to be hospitalised.²⁸ Broomberg (1991) estimated that in 1992 AIDS would account for between 0.9%

and 2% of the total health expenditure of South Africa and that this figure could rise to nearly 40% by the year 2000.²⁹ Being HIV positive is rapidly becoming a family disease where everyone in the family may be HIV infected, have other disabilities and illnesses – as well as having to care for family members who are ill.³⁰

Furthermore, being HIV positive is a chronic disease lasting months or years. According to the World Health Organisation (WHO), the interval between infection with HIV and the onset of clinical symptoms is usually long compared to other communicable diseases and varies considerably between individuals.³¹ The average interval between HIV infection and AIDS symptoms onset is ten years, and from the onset of AIDS, death can occur within one to three years.³¹ Throughout the disease patients experience a wide range of symptoms which include candidal infection, ulceration, diarrhoea, weight-loss, nausea, skin rashes and many others.³² Concurrent infections such as tuberculosis to which HIV positive persons may be more susceptible, also play a role in contributing to the burden of illness.³¹ Presently, in the Western Cape of South Africa there is a tuberculosis epidemic. Health carers and their HIV positive patients need to maintain function and quality of life for as long as possible while being infected.³⁰

Many avenues are being sought to lessen the burden of HIV on the patient and the health care system. One such strategy which is developing in South Africa is the care of the ill at home.³³ The home is increasingly the care option of choice for both sick individuals and health care systems.³⁰ This is due to the increased burden placed upon the health care systems by the rise in AIDS patients as well as the daily rise in HIV positive patients who include infants, children and young mothers as well as older adults.^{28, 34} More attempts are therefore being made to bring basic care into the homes of patients. Patients could then attend hospitals and clinics for the more serious conditions for which tertiary level institutions are intended and so allow very expensive facilities and services to be appropriately used.²⁸

Understanding how common and severe particular groups of symptoms are among HIV positive patients, and how they are being managed will contribute to our understanding of the disease and its treatment. One particular group of symptoms which has received relatively little research attention in the South African context, is the group of oral symptoms.

1.1.3 Oral Symptoms: Importance and prevalence

Most people who are infected with HIV will at some stage present with oral problems, as oral lesions and conditions in the symptomatic phase of HIV infection are prominent features of infection.^{35,36} The WHO lists the following oral conditions as being most closely associated with the symptomatic phases of the disease; candidiasis, angular cheilitis, hairy leukoplakia, gingivitis, periodontitis and atypical ulceration.³⁷ Not only are they often associated with the initial stages of HIV infection, but can herald the onset of AIDS. It is also reported that oral symptoms usually outnumber other signs and symptoms in the early and advanced symptomatic stages.^{35,36} It is important for health care delivery to understand how many patients attending HIV treatment facilities are experiencing oral symptoms and what is being done about them.

Early diagnosis of oral disease is critical as it can ensure that effective treatment is given when there is minimal burden of disease and before significant and irreversible damage is done to host tissues.^{38,39} Early diagnosis and treatment may also prolong and improve the quality of life of people with advanced symptomatic disease.³⁶ It is known that when oral health is compromised, systemic effects of existing gastro-intestinal disorders such as weight loss and diarrhoea, which are common in the advanced stages – can be exacerbated.⁴⁰

Another benefit of early diagnosis of HIV-related oral disease is the provision of chemoprophylaxis for opportunistic infections.⁴¹ Whilst oral lesions can cause significant morbidity, many are responsive to fairly simple therapeutic approaches.⁴¹ Providing patients and health care providers with knowledge regarding oral health care and implementing basic home-care procedures and treatments might become a very necessary feature of the HIV epidemic as health care facilities become overburdened and unable to provide everyone with satisfactory care in the future.

While patients may not recognise or know what to do for their oral symptoms, oral health workers world-wide report a lack of skills in many areas relating to HIV and some of these relate to identification of oral lesions and the treatment thereof.^{42,43,44,45} If patients are taught to be aware of changes to the oral cavity, they can visit the oral health worker at an earlier stage of the disease. Patients might be able to identify areas in oral health care which generally have been neglected, for example, oral prophylaxis and education. They could be taught, together with their carers to

attend to early disease manifestations at home. This mutually beneficial functioning would ensure that carers and health personnel increase their skills and confidence, and that patients obtain more appropriate and timely treatment.^{7, 43, 44, 45}

Finally, earlier diagnosis of oral disease among the general patient population might lead to earlier knowledge of HIV status.^{45, 46} Patients thus detected have the potential and benefit of earlier knowledge or care procedures for HIV in general and oral health in particular. They would then be able to maintain structure and function for a longer time. Other members of the public also can be more effectively protected.

A literature search using Medline, manual searches of sources such as The South African Health Review, and general enquiries to oral health researchers, was undertaken to identify studies which have looked at the prevalence of oral symptoms among HIV positive patients in South Africa. One study was located. This study, still ongoing at the time of enquiry, involved 200 HIV positive patients recruited from outpatients clinics of hospitals in Cape Town. The study reinforced the suggestion that oral symptoms were common: 70% of patients had one or more oral mucosal lesions. Candidiasis was most commonly seen (26%), with the tongue as the most infected site. Nine per cent had angular cheilitis while 25% presented with hairy leukoplakia. The age range of this HIV population group attending outpatients clinics in Cape Town was 20-58 with a mean of 34 years.⁴⁷

However, this study included a relatively small patient sample and did not examine differences in symptom prevalence according to gender. Given the suggestion that HIV is more prevalent and severe in HIV positive females in South Africa,^{8, 14, 20, 21, 22, 23} it is important to establish whether this applies to oral symptoms as well. In addition, although the study by Sauer and Arendorf looked at the presence of symptoms, it did not address severity. The current study will investigate the prevalence and perceived severity of oral symptoms in HIV positive patients in Cape Town and investigate gender differences in these variables.

1.2 The perceived needs of HIV positive patients

1.2.1 Needs assessment

People with HIV face a considerable number of health and social issues and are likely to have a broad range of health care and other needs. Identifying and understanding these needs will be important for delivering quality health care. Patient needs are usually reported by health care professionals or experts (Southern Community Health Research Unit, {SCHRU} 1991). However, expert opinion can be misleading, as experts might not see the full picture of the world from the limited perspective of their own area of expertise.⁴⁸ Experts may not be aware of the dissatisfactions of consumers with existing services and their priorities may not be the priorities of the people they serve.^{48, 49, 50}

In an attempt to move away from clinical assessment of needs, this thesis will focus on patients' assessment of their needs. The Southern Community Health Research Unit (1991) stated that clients and the public being served must be involved in processes which affect them.⁴⁹ Clients also should be informed of the rationale and be able to have input into the consequent setting of priorities. Identification of needs should be a public process where the provision of feedback from patients to those involved in care delivery is crucial.⁴⁸

Denton in Hawe et al. (1990, p 26) defines need as "a state, situation or condition in the community which by its presence or absence reduces, limits or prevents normative function."⁴⁸ Bradshaw, in SCHRU (1991) suggested that there are four different types of need and each is identified using different methods:

1. Normative Needs – what expert opinion defines.
2. Expressed Needs – what you can infer about the health need of a community by observation of their use of services.
3. Comparative Needs – derived from examining the services provided in one area to one population and using this as the basis to determine the sort of services needed in another area with a similar population.

4. Felt Needs – what people in the community say they want or what they think are the problems that need addressing.⁴⁹

This study will focus on the "felt needs" as defined by Bradshaw (SCHRU 1991). Sheiham (1982) and Hawe et al. (1992) interpret this felt need as the individuals' own assessment of her health state.^{51, 48}

Furthermore, in the literature search done through MEDLINE, only one needs assessment concerning HIV/AIDs which focused on the patient rather than the expert was obtained.⁴⁰ This study involved nine program sites located in several United States communities. This is one of the largest studies concerning AIDS patients involving 857 patients. More respondents (52%) reported a need for dental care than for any other service need, with 47% overall reporting oral opportunistic infections. Most of the respondents were identified through community based organisations and were most likely to be white and employed. Whites and intra-venous drug users (IVDUs) were more likely than not-whites and non-IVDUs to report an oral need. In South Africa, the majority of patients who are HIV positive are not white. Their priorities for health care and in particular oral health care, may be different to those reported in Capilouto's study.

Needs assessments may be very useful in determining gaps in services.^{49, 52, 53} According to Sheiham (1982), measures of need should include the impact of ill health upon individuals, the degrees of dysfunction and the perceptions and attitudes of patients.⁵¹ Providing the health care system with feedback on the patients' felt needs across a range of domains will provide valuable information on how the system as a whole is dealing with HIV, and about the areas which patients feel most urgently require addressal.

1.2.2 Domains of patient needs

Patients who are chronically ill with diseases such as cancer, tuberculosis and cardiac illness have unique as well as general needs. This applies equally to the HIV positive patient. A needs assessment provides a direct gauge of the magnitude of patients' desires for help with unmet need.⁵² The literature examining need areas for cancer patients has identified the need to help

patients with the severity of physical symptoms as well as health information and psychological needs as some of the most important need areas.

One study of Australian cancer patients showed that the highest levels of unmet needs for help were reported in relation to health information and psychological issues.⁵² Psychological stress associated with the loss of control, changes in self image and fear of the unknown have all been implicated in the cancer patients' likelihood of experiencing multiple unmet needs in different life areas.⁵²

Several studies have reported significantly enhanced survival outcomes of cancer patients who receive psychosocial interventions in addition to usual medical treatment as compared to patients receiving usual medical treatment alone.⁵² Such studies have shown the importance of identifying and addressing the non-physical needs of patients for optimal prognostic and morbidity outcomes as well as the source of support or need fulfilment.⁵² Factors such as age, sex, socio-economic status, social support and stage of disease all affect the type and magnitude of needs for many chronically ill patients.^{52, 53, 54}

In relation to HIV positive patients world-wide, qualitative studies show that similar to patients with other illnesses, HIV positive patients also require and need support from their families, friends and communities.⁵³ Emotional support is high on the list of needs but financial difficulties are often quoted as prohibiting many patients from utilising services.⁵³ Keele also reports that Canadian women especially highlighted the need for practical assistance in other areas such as medical coverage, affordable housing and insurance.⁵³

Banda, reporting about Zambian home-based care projects, identified counselling, health education, food supplementation, spiritual and material assistance as high priority needs of HIV positive patients.⁵⁴ There has been little research examining the needs of HIV positive patients in South Africa. One study from KwaZulu Natal which involved five health districts and which included qualitative and quantitative methods, identified financial and spiritual support as high need priorities in those areas.⁵⁵ A South African Insurance Aids bulletin published in Cape Town, identifies the needs of the poorer HIV patients as mainly concerning funeral and burial cost and

the provision of education and other costs for the dependent children.⁵⁶ This information was derived from insurance application forms.

In the Western Cape of South Africa only one qualitative needs assessment has been undertaken of about 50 HIV/AIDS patients.³³ This research isolated informational, psychosocial and spiritual needs as being most important to the HIV/AIDS patients. One major issue which emerged from this study was that people in the advanced symptomatic phase had no one to look after them while household members are at work. No previous work examining the perceived needs for help with oral health issues and how these needs relate to other need domains, could be located. There is a need for data on the unmet needs of larger groups of South African HIV positive patients, across a wide range of life domains as well as other pertinent areas which may lead to more effective programs and not merely passive surveillance of trend.²

A search of the literature could not locate a measurement instrument designed to assess the needs of HIV positive patients across a broad range of life domains. Given the potential value of such information, the development of such an instrument, and the collection of broad needs information, is important. The current study will seek to develop and administer an instrument which assesses needs across a number of domains including social, economical, psychological, informational as well as medical and oral health needs. It will also be important to examine whether certain subgroups of HIV positive patients have different needs to others. This will enable greater tailoring of health care services to particular groups. Some variables which it seems valuable to examine in association with needs include gender, symptom level and age.

Women who are oppressed in a number of ways in society and who become HIV positive are likely to have many burdens.^{13, 26} Because women are more vulnerable, health programs should not assume that men and women have similar health experiences and realities.⁵⁷ Men and women often prioritise their health needs differently and any program that does not take this into account will be ineffective.^{13, 26} Redman and others (1988) point out that it has long been argued that women as a group have specific health needs aside from those of the community as a whole.⁵⁷ Given the suggestion that in South Africa females tend to have more rapid progression of HIV, and more severe symptoms, and that women may also suffer burdens associated with social oppression and the family caregiver role, it is possible women may experience greater levels of

unmet needs than men. As no previous work has examined this issue; the current study will examine whether HIV positive men and women in South Africa have different perceived needs.

It is also possible that patients experiencing symptoms may have different needs to those who are not symptomatic. Patients who have multiple infections with increased levels of disability may need greater support, information and/or counselling. No studies have examined this. Finally, no studies have examined whether the age of the HIV positive patient influences their perceived needs. The current study will examine these issues.



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1.3 Research questions, aims and hypotheses

1.3.1 Research questions

1. What is the prevalence and perceived severity of oral disease symptoms of men and women who are HIV positive?
2. What are the perceived needs of HIV positive persons?
3. Do the needs of HIV positive patients differ according their gender, age and whether they have experienced symptoms.

1.3.2 Aims

1. To assess the prevalence and perceived severity of oral disease symptoms among HIV positive males and females of Cape Town South Africa, and to assess whether there are gender differences in the prevalence and severity of oral disease symptoms.
2. To assess the perceived needs of HIV positive persons in relation to social, economic, psychological, informational, medical and oral health domains.
3. To determine whether HIV patients' needs in the above domains differ according to their gender, age and whether they have experienced symptoms.

1.3.3 Hypotheses

Two hypotheses will be tested. Hypothesis 1 relates to Aim 1, and Hypothesis 2 to part of Aim

3.
 1. Among HIV positive patients attending for treatment in Cape Town and its environs, South Africa, between May-November 1995, the reported prevalence and severity of oral symptoms will be higher among females than males.
 2. Among HIV positive patients attending for treatment in Cape Town and its environs, South Africa, between May-November 1995, the perceived social, economical, psychological, informational, medical and oral needs will be greater for females than for males.

CHAPTER 2:

METHODS

2.1 Design

A descriptive cross-sectional survey of consecutive patients attending HIV/AIDS clinics in Cape Town and its environs was used. Eligible and consenting patients completed a structured interview.

2.2 The study sample

The population for the current study was recruited from patients attending HIV clinics in three major provincial hospitals (Groote Schuur, Tygerberg, and Brooklyn Chest Hospitals) and two community clinics (both in Gugulethu) between May and November 1995. These facilities were chosen on the grounds that they had well established HIV clinics and the majority of patients in the Cape would attend these hospitals and clinics for diagnosis and treatment. Although one additional provincial hospital in the area was approached, this hospital did not agree to participate. Patients attending clinics were considered ineligible if they were:-

- (i) under 15 years of age
- (ii) had not had their HIV status confirmed
- (iii) had not yet received post-test counselling about their positive result
- (iv) were severely incapacitated
- (v) had previously participated in the study.

2.3 Procedures

Approval for the study was provided by the Research Ethics Committee of the University of the Western Cape. Permission was obtained from the appropriate hospital authorities to do the research in the various clinical settings. Preliminary visits were made to all clinics to inform the relevant staff of the nature of the research, to answer any questions and to agree upon space and time requirements.

All patients who were of appropriate age, had confirmed HIV status, had received post-test counselling and were not incapacitated were sent to the candidate or trained assistant by the Sister in charge of the clinic at the hospitals. The researchers assessed whether patients had completed the study previously. This involved asking the patients, as names and medical records were not requested on the interview schedule. Patients were seen in a private room. Eligible patients were given an explanation about the research and told that they could refuse to participate or stop the proceedings at any time. Each patient was asked whether s/he was willing or not to participate. This was accompanied by a standard explanatory letter and consent form which was presented to patients as they attended the clinics. Patients could take the form home for further perusal if they so wished and participate at a later date. They were asked to sign a consent form (see appendix a for introductory letter and consent form) at the clinics or in their homes. There were no invasive procedures.

Patients who consented but preferred to be interviewed at home were seen by three fieldworkers. One had received training in filling in the questionnaire and she in turn trained the others. A cool-drink and biscuits were offered if patients were hungry or thirsty and patients were given a 'thank you' health package gift after completion of the interview. An oral health clinic was held on one half day per week for those patients who required treatment, education and oral information. This was a special free, oral clinic held for the study patients.

The clinics attached to the hospitals and those in the community were visited once per week for either one morning or afternoon from May to August 1995. When the patient flow diminished and/or some clinics terminated, the remaining clinics were visited about three times per week.

Reasons for decreased patient flow included that students and other researchers needed to access the same patients, medical and nursing staff taking annual leave and lower patient attendance during the cold, wet, winter months.

2.4 Measures

2.4.1 Development of the measure

A structured interview, which assessed variables relevant to the study aims, principally oral symptoms and unmet needs across a broad range of domains was developed using a number of steps. First, literature and previous studies were examined. This included examination of qualitative data on perceived needs of people in Cape Town,³³ previous measures used to assess unmet needs of cancer patients,⁵² and standard texts on designing questionnaires and improving interview methods.^{58, 59, 60, 61} At this stage, a self-administered questionnaire was devised.

Second, the questionnaire was subjected to peer review. About 20 nurses, doctors, psychologists, dentists and student nurses were involved and provided feed-back. Suggestions about language usage, terminology, length of questionnaire and lay-out were given and steps were taken to address those issues. In the main, questions were included which could inform the later development of an intervention.

Third, the questionnaire was tested for readability and translated into Xhosa and Afrikaans. The questionnaire was initially written in English and the SMOG method used to assess the ease and level of education necessary to read it.⁶² This showed that patients should have attained Grade 5 reading skills (American), which is the equivalent of Standard 3 in South Africa. Standard 3 would be the level of education attained by eleven years of age. The questionnaire was then translated into Xhosa and Afrikaans. The Brislen technique was used for the translation of the questionnaire.⁶³ This involved setting the questionnaire in English, translating into Afrikaans and Xhosa from the English version and then translating back from the Xhosa and Afrikaans into English to ensure that the original meaning was maintained. Covering letters and explanations about consent, confidentiality and details about the project were similarly translated. As

previously indicated, at this stage a self-administered questionnaire was used and the candidate and assistant would assist in matters of clarification.

Fourth, the measure was pilot tested, as described below.

2.4.1.1 First pilot study

The questionnaires were piloted at Groote Schuur and Brooklyn Chest Hospitals. In total, 19 patients were recruited for the first pilot phase. However, five patients were too ill to participate, resulting in 14 patients completing the questionnaire. The candidate and the research assistant kept a diary of events in the clinics.

It took on average about 45 minutes to complete the questionnaire. Overall, this was unacceptable to the patients and to the nursing and medical staff. The introductory explanation and request for consent was too long and complex. Patients found the introduction more acceptable when specific benefits of the study were mentioned. Due care was taken not to raise patients' expectations.

The refinement of the questionnaire involved elimination of a number of questions on the grounds of irrelevancy, cultural bias and redundancy. The literacy levels encountered were very low. As patients took a long time to complete the questions, with many expressing discomfort, it was decided to change to a structured interview format.

The structured interview necessitated that the candidate, trained assistant and fieldworkers be standardised in their delivery, particularly in relation to the introduction, asking the questions, and to giving similar explanations when required. Workshop sessions were held where-in these matters were practised and education around HIV issues provided. The fieldworkers were all working in a home-based care project for HIV/AIDS patients. They had been involved in needs assessment research previously and were therefore assessed to be experienced and knowledgeable in the area of HIV/AIDS fieldwork.

To assist patients in answering the needs section, a card which indicated the response choices was developed. The card was shown to patients during this section of the interview.

2.4.1.2 *Second pilot study*

The shortened interview version was piloted with thirty patients seen at the Groote Schuur and Tygerberg hospitals as well as the Ulunthu community clinic in Gugulethu. The interview took 15 minutes to complete and was more acceptable to patients and clinic staff. It took longer to administer depending on the patients' degree of illness, literacy levels or other compounding factors. The card system helped to focus some patients on the response options. An opportunity was made available for patients to ask questions at the end of the interview. The knowledge that a back-up service was offered at a dental clinic in a specific community appeared very acceptable. During this phase four patients refused to answer the questionnaire. This gave a consent rate of 88%. Pilot testing showed all patients were Afrikaans and Xhosa speakers, approximately 30 per cent and 70 per cent respectively. At this stage we also established that some Xhosa speaking patients chose to use the English questionnaire. Negligible changes were made to the questionnaire after this phase.

2.4.2 *Variables in the final measure*

The structured interview assessed variables within three sections namely, demographics, needs and a combination of medical and oral history. The interview is shown in Appendix a. It should be noted that the thesis will not report on all variables contained in the interview. A description of the variables of relevance are given in the following sections.

2.4.2.1 *Demographic characteristics and medical history*

This section collected information on gender, age, area of residence, employment status, income, language spoken, population group, number of children, marital status, educational level, number of people in the home, organisations to which patients belonged and who gave assistance to the patient in the home.

Patients were also asked how long it was since they had been diagnosed HIV positive, and whether they had a history of the following five conditions, either before or after HIV was diagnosed: diabetes, tuberculosis, sexually transmitted diseases (eg. gonorrhoea), epilepsy and heart problems.

Patients were also asked about their current experience of general symptoms associated with HIV. Patients were asked whether they presently had the following nine symptoms: tiredness, chest problems, weight loss, nausea, diarrhoea, skin rashes, swellings, fevers and infections. Those who reported currently experiencing two or more of these were considered to be symptomatic.

2.4.2.2 Oral health history and practices, oral symptoms and their severity

The oral health history and practices items assessed whether patients had their own teeth (none, some, most, all): whether they currently brushed their teeth (never, occasionally, several times a week, once daily, more than once daily); and whether they had received any of the following four oral treatments, either before or after HIV was diagnosed; oral education and instruction (someone telling you how to look after your mouth); scale and polish (teeth cleaned), extractions and fillings.

Patients were also questioned about which service types they would use if they had a broken tooth. They were asked whether they would go to the following three public services (hospital, clinic, community nurse), or whether they would go to the following two public services (traditional healer, private dentist).

To assess oral symptoms, patients were asked whether they had any of the following symptoms either before or after HIV was diagnosed: bleeding gums, rotten teeth, mouth ulcers, loose teeth, pain, bad breath, swollen gums, red gums, white, furry tongue, chewing problems, plaque, calculus, stains or any other problems. Patients who reported experiencing any of these symptoms were asked whether they were presently experiencing any problems with their mouth. The symptoms listed were derived from previous literature on common oral problems in the general community and HIV patients in particular. In order to be brief, atypical ulceration, human papilloma virus and stomatitis which patients may report, were coded under the heading of "ulcers". Candidal infection of the tongue was referred to as "white furry tongue."

The above conditions are listed under the WHO classification of "Oral manifestation of HIV disease" as conditions very strongly associated with being HIV positive and the conditions most likely to be encountered in HIV positive patients.³⁷ To assess symptom severity, patients who reported having experienced each symptom were asked to rate it as mild, moderate or severe.

2.4.2.3 Needs

The format for this was based on the Cancer Patients Needs Questionnaire.⁵² It consisted of 31 statements, in which patients were asked whether they needed help with specific issues on a scale of 1-4 where:

- | | | |
|---|---|---------------|
| 1 | = | No need |
| 2 | = | some need |
| 3 | = | moderate need |
| 4 | = | high need |

The items were designed to reflect needs within five domains. The broad domains and the number of items within each, are outlined below.

- | | | | |
|----|--|---|---|
| a. | <i>Social</i>
(6 items) | - | perceived need in relation to physical support/practical support in the home, literacy needs. |
| b. | <i>Economic</i>
(3 items) | - | need for water, electricity, to generate income from home. |
| c. | <i>Psychological</i>
(8 items) | - | help with stress, smoking and drinking problems, fears of being left alone, sleeping behaviour, sexual problems and difficult family relationships. |
| d. | <i>Medical & Oral</i>
(8 items) | - | needing nursing care, help in taking medications, need to increase energy levels, exercise more, better self-care, need for dentures, help with bad breath relief from oro-facial pain. |
| e. | <i>Informational</i>
(6 items) | - | to recognise disease, where to go for help, disability grants, oral diseases, where to go for emergency treatment and help, where to get community support. |

The need questions applied to those needs experienced by the patients at the time of questioning.

2.4.3 Analysis

The computer packages used for the analysis were SAS and BMDP 4M. The following analyses were undertaken: Descriptive statistical analysis, principally frequencies, were used to summarise the demographic and medical history characteristics of the sample.

Aim and Hypothesis 1:

Descriptive statistical analysis was performed, principally frequency distributions to examine symptom prevalence and severity. To test for differences between gender groups, Chi square tests were done.

Aim and Hypothesis 2:

Exploratory Factor analysis was undertaken to assess the construct validity of the needs instrument, in order to explore the need domains. The program BMDP 4M was used. Cronbach's alpha was used to test the internal consistency of the factors. Descriptive statistics were used to summarise data for each needs item. The items were ranked in terms of the percentage of the sample who expressed a moderate or high level need.

Aim 3 and Hypothesis 2:

The mean scores on each needs factor were compared using t-tests for gender groups and groups of patients who were not symptomatic. One way analyses of variance were used to assess differences between age groups.

CHAPTER 3:

RESULTS – THE PREVALENCE AND PERCEIVED SEVERITY OF ORAL SYMPTOMS IN HIV POSITIVE PATIENTS

This chapter describes the characteristics of the sample in terms of demographic characteristics, medical history as well as prevalence and severity of oral disease symptoms. Aspects relating to aim and hypothesis 1 will be reported.

3.1 Eligibility and consent rate

Of a possible 448 patients, 103 (23%) were ineligible: 10 due to severe incapacitation, one being under age, 20 not having had their HIV status confirmed, 35 not having been counselled and 37 were not included due to the nature of patient flow in the specific clinic or having filled in the questionnaire already. Of the remaining 345 eligible patients, seven (2%) refused consent, yielding a response rate of 98%. The final sample to be included in the study consisted of 338 patients. One hundred and sixty four (49%) patients were seen at the hospital clinics while the remaining 174 (52%) were seen at the community clinics and in their homes. Thirty patients of the 174 (20%), were interviewed in their homes, rather than in the care facility from which they were recruited. All of those interviewed at home were recruited from community clinics.

3.2 Demographic and general characteristics

Table 1 shows the demographic characteristics of the sample by gender. The females comprised 62% of the sample. The ages ranged from 16 to 66 with the mean age being 32 and standard deviation 9.0. The age group into which the largest proportion of the sample fell was the 25-34

year age group which contained 42% of the sample. Eighty-two percent said they were from the city and its environs while the rest came from semi-rural or rural areas.

The majority of the patients were Xhosa speakers (76%). The second largest group (21%), were those persons designated in the past as "coloureds," who spoke Afrikaans. Only 2% were English mother-tongue speakers and 1% came from other groups such as Indians, Sotho and a few non-nationals from neighbouring states. Fifty-eight per cent were either single, widowed or divorced and 41% were married or living together in a relationship. Of the sample, 26% reported having had primary level education with standard 4 as the most often reported leaving standard (just two years short of completing junior/primary schooling) while 70% said secondary school with standard eight as most often reported passing out standard (two years short of matriculation). Four per cent mentioned having attended university with only a few having completed degrees or diplomas. Forty-three per cent were unemployed. The question on family income was poorly answered with missing data for 30% of the sample. Of the 239 who responded to this question, 32% reported a household income of less than 300 rands per month (about A\$ 111 to 320).

Responses to other items not shown in Table 1 showed that the mean number of persons in patients' households was five (standard deviation = 3.7). Fifty-two per cent reported that they belonged to a church group and 24% to a civic organisation. When asked who gave the most help to the patient in the home, 24% maintained that they were helped mostly by a parent, usually the mother; 17% of patients were helped by a brother or sister, usually a sister; 12% by either the wife or husband, usually the wife.

3.3 Medical characteristics

Table 2 shows the medical history characteristics and current symptom level of the sample, by gender. Almost three quarters of the sample had been diagnosed within the last year, with only a small proportion of patients having been diagnosed for over three years. Fifty-five per cent of patients had ever been infected with tuberculosis. Twenty-seven per cent of the sample reported having had/having STDs. Although the data presented are for conditions experienced either before

or after HIV was diagnosed, anecdotally patients reported having had most of these medical conditions and symptoms prior to being diagnosed and that having these diseases often led to the diagnosis of HIV. As outlined in Chapter 2, patients who currently had two or more symptoms such as weight-loss, diarrhoea, other infections and skin rashes were considered to be symptomatic. Those who had one or no symptoms were considered to be asymptomatic. Eighty-six per cent of the patients reported being symptomatic.

3.4 Oral health history and practices

Table 3 shows data on oral history and practices. Overall, 55% of patients reported having all their own teeth. The proportion of women with all of their teeth was higher than men. Overall, 35% of the sample had ever had oral education and instruction, and 36% oral prophylaxis (scaling and polishing). Twenty four per cent reported fillings, but 64% extractions. There were no significant gender differences on these variables.

In relation to the type of services patients reported they would use if they had mouth problems, 62% of the men reported they would go to public services such as clinics, community day hospitals as opposed to 56% of women. Private dentists or traditional healers were chosen by 52% of the men and by 60% of the women. Again, these differences were not statistically significant. Forty-one per cent reported brushing their teeth one or more times per day. Women were more likely than men to brush more than once a day. This difference was statistically significant.

Table 1: Demographic characteristics of the participating patients, by gender

Characteristic	Males n = 128		Females n = 210		Total n = 338	
	n	%	n	%	n	%
Age						
16-24	10	8	67	32	77	23
25-34	51	40	90	44	141	42
35-44	50	39	37	18	87	26
44>	16	13	13	6	29	9
Area						
semi-rural/rural	33	26	29	14	62	18
urban	95	74	181	86	276	82
Population						
coloured	50	39	20	10	70	21
Xhosa	68	53	187	89	255	76
white	4	3	1	0.5	5	2
Indian	0	0	2	0.5	2	1
other	4	3	0	0	4	1
Employment status						
employed	78	61	114	54	192	57
unemployed	50	39	96	46	146	43
Marital status						
single/divorced/widow	60	48	137	65	197	59
married	64	52	73	35	137	41
Education						
primary	41	34	43	21	84	26
secondary	71	59	159	76	230	70
tertiary	8	7	7	3	15	4
Family income						
<R300	24	19	53	25	77	32
R300-500	18	14	35	17	53	22
R500-1000	28	22	25	12	53	22
R1000-2000	8	6	15	7	23	10
>R2000	6	5	4	2	10	4
Other	4	3	19	9	23	10
Have children						
yes	120	94	201	96	321	95
no	8	6	9	4	17	5

Missing data for some characteristics, sample sizes vary between 239-338 for total sample.

Table 2: Medical history characteristics of the sample, by gender

Characteristic	Males n = 128		Females n = 210		Total n = 338	
	n	%	n	%	n	%
Time since HIV diagnosed						
within last year	96	76	147	71	243	73
2-3 years ago	21	17	54	25	75	22
>3 years	10	8	7	3	17	5
Ever had Diabetes						
yes	11	9	37	18	48	14
no	117	91	173	82	290	86
Tuberculosis						
yes	74	58	113	54	187	55
no	54	42	96	46	150	45
Std's						
yes	40	31	52	25	92	27
no	88	69	158	75	246	73
Epilepsy						
yes	15	12	26	12	41	12
no	113	88	184	88	297	88
Heart problems						
yes	10	8	31	15	41	12
no	118	92	179	85	297	88
Symptomatic						
yes	117	91	173	82	290	86
no	11	9	37	18	48	14

Missing data for certain characteristics. Sample sizes vary between 336-338.

Table 3: Oral health history and practices of the study population, by gender

Oral Factors	Males n = 128		Females n = 210		All n = 338		p-value χ ²
	n	%	n	%	n	%	
Own teeth							
none	14	11	20	10	34	10	0.019
some	56	44	63	30	119	35	
all	57	45	126	60	183	55	
Ever had: Oral education and instruction:							
yes	41	32	76	36	117	35	ns
no	87	68	134	64	221	65	
Scale and polish:							
yes	39	30	83	40	122	36	ns
no	89	70	127	60	216	64	
Extractions:							
yes	89	70	127	61	216	64	ns
no	39	30	83	39	122	36	
Fillings:							
yes	26	20	54	26	80	24	ns
no	102	80	156	74	258	76	
If had problems would use public service:							
yes	79	62	117	56	196	58	ns
no	49	38	93	44	142	42	
Private service:							
yes	67	52	126	60	193	57	ns
no	61	48	84	40	145	43	
Currently brush teeth:							
never	7	6	6	3	13	4	0.026
occasionally	14	11	15	7	29	9	
several times a week	10	8	19	9	29	9	
once a day	58	45	71	34	129	38	
more than once daily	39	31	99	47	138	41	

Missing data for certain characteristics. Sample sizes vary between 336-338.

3.5 Oral symptoms

Table 4 gives information about the prevalence of oral disease symptoms by gender, and reports the results of chi-square analysis comparing the gender groups. The symptoms are ordered in terms of the proportion of the overall sample reporting the symptom. Generally, prevalence of symptoms for females and males were very similar with only one symptom showing a statistically significant difference between males and females. More males (41%) than males reported calculus (26%). The most commonly reported symptoms were bleeding gums, decay teeth, oro-facial pain, candidiasis and plaque which were experienced by at least 40% of the sample. The proportion of males (n=128) reporting they were currently having problems with their mouth was 72%. The corresponding figure for females (n=210) was 66% and for the overall sample it was 68%. Chi-square analyses showed the percentage currently experiencing oral problems did not differ significantly between gender groups ($p>0.05$).

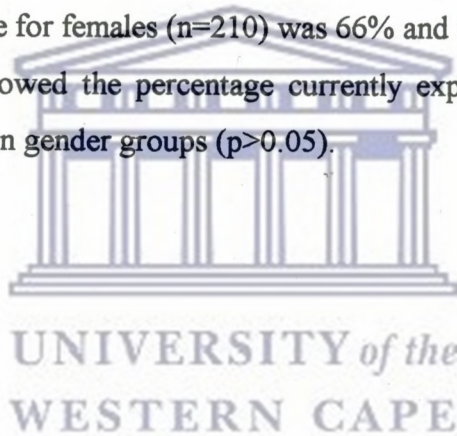


Table 4: Reported prevalence of oral symptoms since HIV diagnosed, by gender

Symptom	Males n = 128		Females n = 210		All n = 338		p-value χ ²
	n	%	n	%	n	%	
Since HIV diagnosed							
- bleeding gums	64	50	95	45	159	47	ns
- decayed teeth	64	50	89	43	153	45	ns
- candidiasis	55	38	89	43	144	43	ns
- oro-facial pain	50	39	90	43	140	42	ns
- plaque	48	61	77	37	138	41	ns
- ulcers	42	33	82	39	124	37	ns
- bad breath	46	36	72	34	118	35	ns
- calculus	52	41	53	26	105	32	0.005
- chewing problems	40	43	68	42	18	32	ns
- red gums	33	26	33	102	102	30	ns
- staining	44	34	52	25	96	29	ns
- swollen gums	27	21	54	26	81	24	ns
- tooth mobility	24	19	48	23	72	21	ns
- other e.g. trauma, tumours	12	9	15	7	27	8	ns
- Presently experiencing oral problems	92	72	139	66	231	68	ns

Missing data for some symptoms. Sample sizes vary between 330-338.

3.6 Severity of oral symptoms

The severity ratings were examined for each symptom. Two (male/female) by four (none, mild, moderate, severe) severity, chi-square analyses were conducted to see if there were gender differences in perceived severity. Of the 14 symptoms, significant differences emerged on one. The results for this symptom is shown in Table 5. Males were more likely to report severely decayed teeth and less likely to report mild decay than females.

Table 5: Perceived severity of decayed teeth, by gender

Symptom	Gender n = 338 n	% rating severity as:				p value χ ²
		none %	mild %	mod %	severe %	
Decayed Teeth	male	32	6	19	44	0.029
	female	34	15	20	32	

* The "none" category represents those who did not report the symptom.

CHAPTER 4:

RESULTS – THE PERCEIVED NEEDS OF HIV POSITIVE PATIENTS

This chapter consists of three sections. The first describes the analysis of the psychometric properties of the needs questionnaire; exploring the construct validity (through factor analysis) and internal reliability (through Cronbach's alpha). The second describes the level of needs reported by the sample. The third examines levels of need against gender, age and whether patients are currently symptomatic. The results presented address Aims 2 and 3, and Hypothesis 2.

4.1 Psychometric analysis of the needs questionnaire: construct validity and internal consistency reliability

4.1.1 Construct validity

Exploratory factor analysis was undertaken to explore the construct validity of the needs questionnaire. The principal components method of factor analysis was performed on the 31 item questionnaire using the BMDP 4M program. The principal components model enables the exploration of dimensions underlying patients' perceptions by summarising data into an optimal number of independent factors. Squared multiple correlations were used as the initial commonality estimates, and the commonality estimates were iterated. A varimax rotation was performed on all factors satisfying Kaiser's criterion that only factors with an eigenvalue or sum of the squared factor loadings, of 1.0 or more, be retained.

The program identified eight factors with eigenvalues greater than 1 which together accounted for 63% of the total variance. Additional runs of the factor analysis were performed, in which 7, 6, 5 and 4 factor solutions were examined. All the reductions were explored and the reduction to six factors made the most conceptual sense and most closely approximated our initial domains. Thus the six factor solution was chosen for further examination. The six factors accounted for 55% of the variance. Items with factor loadings of over 0.250 were included and items were

considered to belong to the factor or 'scale' on which they had the highest loading. The factors and the items within each factor, together with the proportion of the total variance explained by each factor, as well as the final commonalities and eigenvalues were identified and are reported in appendix b.

The six domains or factors identified through the analysis process were as follows:

- Domain 1:** *socio-economic needs* – 7 items: taps into a range of basic issues including need for water supply, electricity and better care in the home.
- Domain 2:** *informational needs* – 8 items: the domain taps the need for information about a range of disease issues and service availability.
- Domain 3:** *psychological needs* – 5 items: Includes need for help with family relationships and discussing HIV with the family, as well as drinking and smoking.
- Domain 4:** *social support needs* – 3 items: taps the need for support from family, friends and community.
- Domain 5:** *oral and medical needs* – 6 items: include need for help with pain relief, bad breath and false teeth and sleeplessness.
- Domain 6:** *physical needs* – 2 items: includes the need to exercise more and get out more often.

The six domains or scales thus contain 28 of the original 31 items. The domains or factors correspond closely to those hypothesised a priori and were found to be measuring the same

underlying constructs generally. The items were fairly consistent but ordered slightly differently in the factors than initially ordered. Initially, economics had been a separate domain but as there were very few economic items in the domain, the inclusion of economics in the social domain was a practical solution.

4.1.2 Internal consistency reliability

A special case of Cronbach's alpha, Carmines theta, was used to calculate the internal consistency of the six domains or scales. The values were over 0.9 for all six factors. This value reflected the standardised Cronbach's alpha and indicates high levels of internal reliability.⁶⁴ Some parsimony was achieved which also contributes to increasing the reliability and validity of the measure.⁶⁵

4.2 Level of Needs: Responses to needs questionnaire

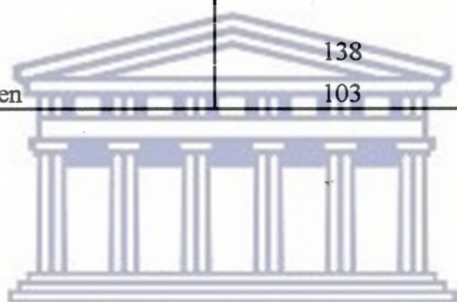
The proportion of the sample indicating they had a moderate or high need on each item was calculated. Table 6 reports the percentage of the sample indicating moderate or high needs for items within each factor. The table also ranks the 28 items in terms of the proportion of the sample indicating moderate or high need. The 10 items for which the highest proportion of the sample reported a need are shown in bold.

It can be seen that at least 25% of the sample reported moderate or high need on all 28 items. At least half the sample reported moderate or high needs on 15 items. Of the ten items for which the highest proportion of the sample rated a need, six were in the informational domain, with the highest ranked items being the need for information about disability grants and the need for information about mouth diseases. All of the six items in the informational factor were among the top ten needs. Of the remaining items in the top ten, one fell within the medical-oral domain (help in coping with stress); one in the socio-economical (help with a job at home); one in the psychological (help in coping with fears about being left alone) and one in the support domain (need for support from friends).

Table 6: The percentage of the sample indicating moderate or high needs on each item

Fact and Items	Mod/High Needs n = 338		Rank
	n	%	
Factor 1: Socio economic			
Do you need:			
– a job at home	213	63	5
– nursing home-care	175	52	11
– to improve your writing	173	51	13
– to care better for yourself	170	50	15
– to improve your reading	169	50	14
– electricity in the home	146	43	18
– tap water in the home	126	37	22
Factor 2: Informational			
Do you need information:			
– about disability grants	255	75	1
– about mouth diseases	241	71	2
– to recognise simple diseases	220	65	3
– written information about how to handle your illness at home	204	60	6
– about community organisations	199	59	7
– emergency treatment and help	191	57	8
Factor 3: Psychological			
Do you need help:			
– in coping with fears about being left alone	187	55	9
– in talking to the family about being HIV+	136	40	20
– in coping with difficult family relationships	131	39	21
– to stop smoking	109	32	25
– to stop drinking	85	25	28
Factor 4: Support			
Do you need:			
– more support from friends	182	54	10
– more support from family	118	35	24
– more support from community	97	29	26

Fact and Items	Mod/High Needs n = 338		Rank
	n	%	
Factor 5: Medical-oral			
Do you need:			
- help in coping with stress due to the illness	216	64	4
- more energy for selfcare	174	52	12
- help in coping with sleepless nights	166	49	16
- relief from pain	158	47	17
- to be rid of bad breath	125	37	23
- false teeth	87	26	27
Factor 6: Physical			
Do you need:			
- to exercise more	138	41	19
- to get out more often	103	31	25



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4.3 Examination of need levels against gender, age and symptom level

Scores on each of the factors were calculated by adding responses to component items. Items were scored no need = 1, low need = 2, moderate need = 3, high need = 4. Hence a higher score on a factor indicates a higher level of need. On an eight item scale, potential scores range from 8 (no need on any item) to 32 (high need on all items).

Table 7 shows the results of analyses comparing mean scores on each factor for patients grouped according to gender, age and being symptomatic or not. Being symptomatic was defined as having two or more general symptoms such as tiredness, weight-loss, diarrhoea and skin rashes. For the characteristics gender, age and being symptomatic, the boxplots and graphs of scores on each factor were examined for each subgroup. The distributions were sufficiently normal to allow t-tests (for gender, symptomatic) and Anova (for age) to be conducted. The mean factor scores across all six factors were fairly similar for males and females. However, females scored significantly higher than males on the informational domain. The result for factor 1: socio-economic, was just beyond significance. Factor scores for the symptomatic and asymptomatic groups were significantly different on factors one, two, three and five, with the symptomatic group showing higher need in those domains, namely socio-economic, informational, psychological, and support. A similar result was recorded for factor three, although the difference was just beyond significance. There were no significant differences between age groups.

Table 7: Mean factor scores and results of statistical tests

Characteristic	N	F1: Socio-economic		F2: Informational		F3: Psychological		F4: Medical-oral		F5: Support		F6: Physical	
		Mean	Std	Mean	Std	Mean	Std	Mean	Std	Mean	Std	Mean	Std
Gender:													
MALE	127	16	6.8	16	5.3	11	4.7	8	3.2	14	5.2	4	2.0
FEMALE	207	18	6.7	17	5.2	11	4.6	8	2.9	14	5.3	4	2.1
		tt =	-1.9	tt =	-2.15	tt =	0.022	tt =	-0.98	tt =	0.002	tt =	-1.07
		df =	(125,204)	df =	(127,205)	df =	(125,207)	df =	(127,207)	df =	(126,206)	df =	(207,127)
		p =	0.057	p =	0.034	p =	0.956	p =	0.387	p =	0.941	p =	0.306
Symptomatic													
YES	290	17	6.8	17	5.2	11	4.7	8	3.0	14	5.2	4	2.1
NO	48	14	6.5	15	5.4	9	4.2	8	2.9	11	4.5	4	1.8
		tt =	-2.938	tt =	-2.741	tt =	-2.1074	tt =	-1.1391	tt =	-5.261	tt =	-1.378
		df =	(282,47)	df =	(285,47)	df =	(285,47)	df =	(287,47)	df =	(285,47)	df =	(287,47)
		p =	0.006*	p =	0.007*	p =	0.056*	p =	0.250	p =	0.000*	p =	0.263
Age													
16-24	73	17	6.9	17	5.4	10	5.0	8	2.7	13	5.2	4	1.8
25-34	141	17	7.1	17	5.4	11	5.0	8	3.1	14	5.4	4	2.1
35-44	87	16	6.6	17	5.1	11	5.0	8	3.2	14	5.1	4	2.1
>45	28	16	5.6	17	5.0	9	4.0	8	3.2	14	4.8	4	1.9
		Anova =	0.25	Anova =	0.08	Anova =	1.63	Anova =	0.39	Anova =	1.75	Anova =	1.72
		df =	(325,328)	df =	(326,329)	df =	(326,329)	df =	(328,331)	df =	(327,330)	df =	(328,331)
		p =	0.859	p =	0.969	p =	0.183	p =	0.760	p =	0.157	p =	0.162
*		Numbers differ slightly due to missing data.											
*		Minimum and maximum scores for each factor are:											
		F1: 7-28	F2: 8-32	F3: 6-24	F4: 3-14	F5: 6-24	F6: 2-8						

CHAPTER 5:

Discussion

The discussion will include the strengths and limitations of the study, aspects relating to oral health symptoms and practices, needs, the conclusion and recommendations.

5.1 Strengths of the study

5.1.1 Representativeness

As the sample population was obtained from community clinics and provincial hospitals, it represented a good mix of all HIV clinics. Most of the clinic facilities in the area were sampled. Had the sample been confined to provincial hospitals, patients who only present at community clinics would have been missed.

Studies done in the Cape Town area, such as that by Sauer and Arendorf (1994), have only used the provincial hospital clinics. This is one of the few studies which has included community clinics. Many patients choose to go to community clinics because they find the hospital clinics too "sanitised" or it is time-consuming and costly in terms of travelling expenses to get there. In contrast, many researchers choose only to research in the hospital clinics because it is very convenient. In total, 52% of the sample population were recruited through community clinics.

The demographic breakdown of the sample population was very similar to the broader figures available on characteristics of HIV positive persons in South Africa. For example, 62% of the sample were female which is consistent with national estimates of the gender distribution among HIV positive patients. Tuberculosis and STD rates also closely approximate the national rates closely.

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5.1.2 Content

This study is the first in Cape Town to examine the issues of oral symptoms and the broad needs of HIV positive patients. In relation to oral health, it was the first in South Africa to examine gender differences and severity of conditions for patients who were mostly in the early symptomatic stage of the disease. The study also represents the first quantitative examination of the needs of HIV positive patients in South Africa across a broad range of life domains and of the age and gender differences in need level.

5.1.3 Consent rate

A high consent rate of 98% was obtained in this study which is rarely encountered in HIV studies using other methodologies. This is further evidence for the representativeness of the sample.

5.1.4 Standardisation of the measure

The measure was a standardised interview which was developed using standard psychometric techniques. The needs instrument has established construct validity and internal consistency reliability.

5.2 Limitations of the study

5.2.1 Sample representativeness

Although the sample appears to be a good representative sample of HIV positive patients attending clinics, there may be some HIV positive patients who do not attend treatment in HIV clinics, or do so very infrequently, thus lessening the chance they would be represented in the sample. Therefore one cannot be very certain how well the sample represents all the diagnosed HIV positive patients in Cape Town and the environs. However, accessing those not in contact with the hospital and clinic health systems would have been difficult and costly.

5.2.2 Test-retest reliability

It was not possible to assess the test-retest reliability of the measure as the need for anonymity was paramount. In addition, patients could not be asked to return in one or two weeks because of travelling costs and other constraints. Imposing further burdens on the patients had to be avoided.

5.2.3 Self-report bias

Some potential limitations are present due to the use of self-report data and to the actual questions asked. This is particularly relevant to the oral symptoms and practices section. Symptom levels for a number of specific symptoms, based on self-reported levels since HIV was diagnosed (which varies between patients and may have existed in some for 5 years and more) were asked, with only one general item on current problems. This data potentially suffers from under or over reporting. Patients may not have recognised symptoms or forgotten they had them (leading to under-reporting) or may have recalled symptoms which did not occur (resulting in over-reporting). We do not know the extent to which this is the case in terms of the magnitude of problems reported, suggesting these data have some validity. However, the results are comparable with other data in which oral examinations have been used to assess symptom level.

The field diaries kept by the candidate and research assistant also suggest that even though the symptom items asked patients to recall symptoms since HIV was diagnosed, most gave the impression that their answers were actually reflecting their symptoms at the time of the interview. This could have been due to the fact that since 73% of patients were diagnosed HIV positive within the last year – symptoms had been relatively recent. This suggests that the figures may represent an under-reporting of the total period since HIV was diagnosed. In retrospect, it may have been better to ask about symptoms currently experienced or experienced say, in the last month. An objective assessment of patients' mouths would have improved the study but this was

foregone because of time constraints, fear of over-burdening the patient and because information is available from studies in which clinicians examined HIV positive patients' mouths. Some of these studies are still ongoing.

The educational levels of the study population was generally low with nearly 50% achieving standard 2 or 4 schooling levels only, and about 40% reaching standard 6 or 8 levels. Because of this, some patients had difficulty understanding the concepts and certain questions were problematic, despite explanations. This suggests that accurate information may not have been obtained from these patients. There may also have been biases created by social desirability, particularly given the sensitive nature of certain items.

Under reporting would seem to be particularly applicable to this study, especially the needs items, not only because of the sensitive nature of certain items, but also because of the nature of the disease, the stigmatisation attached to it and the assumptions made by the patient in relation to the interviewer. Patients may have been reluctant to admit to 'not coping' and under-reported their needs. Patients might also have felt threatened or intimidated by the inter-action and either under or over reported.

5.2.4 Inter-rater reliability

Although all people gathering data were given training – there may have been differences between interviewers in how they delivered the interview. Minimal checks were conducted throughout the period of data collection. Patients may have responded differently to different interviewers due to the way the interviewer asked the questions. Interviewers may have selectively reinforced some answers to motivate interviewees and elicit responses when none were forthcoming. Patients may also have been more reluctant to answer sensitive items truthfully, for example, the questions on income, sexual or drinking problems, depending on the interviewer. It is difficult to know the extent to which such biases operated.

5.2.5 Analysis

The needs analysis was based on bivariate analyses examining whether age, gender and symptom level affected the level of need. The study did not include multi-variate analyses such as regressions. Such analyses would have allowed the contributions of age, gender and other

variables such as time since diagnosis to be examined in relation to need levels, in a way which controls for interaction between the predictors. Similarly, multi-variate analyses may have been useful for examining the contribution of variables to oral symptom level.

5.3 Sample characteristics

The majority of patients were poverty stricken and poorly educated. Literacy levels were very low. Just under 50% of the patients were unemployed and home-bound and the low socio-economic situation of the majority of the participants who answered the question about monthly household income, 54% said that they earned between 300 and 1,000 rands (about A\$ 111-370) per month per household. Studies have consistently found that there is an association of lower socio-economic status with increased morbidity and mortality in HIV patients, as well as with other diseases and risks in the general population, and that younger persons of low socio-economic status are apparently at greater risk than those of higher socio-economic status.^{66, 67}

Seventy three per cent of the patients were diagnosed HIV positive within the last year. The patients were also mostly young adults, 65% being under 35 years of age. Over half of the patients had had tuberculosis while 27% had had STDs. The majority (86%) were classified as symptomatic on the basis of the presence of two or more general symptoms. From the recency of the diagnosis, the capacity of the patients and the observations of fieldworkers and the candidate – it appeared that most patients were in the early symptomatic stages of the disease, especially the women, and that most patients had not developed AIDS. The degree to which patients were symptomatic would have affected their experience of oral symptoms and needs.

Fifty two per cent of the patients belonged to church organisations. The church appeared important in the lives of these patients and this could have implications for considering a wider role which such organisations could potentially have in the care and support of HIV positive patients. In relation to care in the home, over half of the patients maintained that they received assistance from a female. These figures are reflective of the HIV picture for the rest of Southern Africa.

5.4 Oral health symptoms and practices

The high rate of symptoms experienced by the patients in this study mirrors the work of Sauer and Arendorf (1994), and is reflective of the level of symptoms experienced in the general population of South Africa.⁶⁸ The five most common symptoms were bleeding gums, decayed teeth, candidiasis of the tongue, pain and plaque which had all been experienced by at least 40% of patients. Sixty-eight per cent were currently experiencing oral problems. Sauer and Arendorf's study reported that 70% HIV positive patients presented with oral problems.

The hypothesis that females would have greater severity and more oral symptoms than males was not supported. Gender differences occurred only for the symptom, calculus, and on this symptom more males reported having calculus than females. There was also only one item on which the genders differed, namely severity, with males more likely than females to rate decayed teeth as severe.

Although the analyses performed in the current study do not support the premise that females suffer greater levels or severity of oral symptoms than males, it would be interesting to further examine patterns and progression of oral disease in HIV positive patients of different genders. The current study did not undertake multivariate analyses to examine the impact of gender on symptom level while controlling for the impact of other variables such as age, disease duration and previous care.

In the current sample the females were younger. Seventy-five per cent of the women were in the 16 to 35 year age group as opposed to 48% of males. Because more men were in the older group, it may not be surprising that they reported equal or greater prevalence and severity of oral symptoms. Women are also generally diagnosed earlier than men because they visit ante-natal clinics and health clinics more often than males.⁵⁷ This could have contributed to better oral health in women and could have resulted in females having less oral symptoms than males. This could also explain why men experienced more severe rotten teeth than women.

Women may potentially also have received different care to males, many having visited an antenatal clinic and potentially having had more frequent contact with health workers. Men could have had less previous care or deferred treatment for longer times than women. It could also be that the reason why HIV positive women and men showed similarities in oral signs and symptoms was a more rapid progression of oral disease conditions in women.

Given these issues, further sophisticated analysis is warranted. It would be desirable for such further examination to use a tighter definition of oral symptom presence.

The oral practices information also approximates the oral situation found in the majority of the general South African population. Oral hygiene is as poorly practised among HIV positive patients as in the general population. Extractions remain the most frequently performed treatment modality (64% had an extraction) with fewer men or women having fillings (24%), oral prophylaxis, instruction and education. Despite the fact that most patients had received some dental care and had experienced oral symptoms, only a third of the patients recalled ever having an oral prophylaxis or receiving oral education and instruction. This is clearly less than optimal especially since most patients do report brushing daily, an aspect of patient behaviour in this population group which could be more effectively harnessed for oral education and instruction.

Fifty-seven per cent of the patients indicated that they would choose to attend private dental clinics rather than community ones. Some of the possible reasons for this are that patients attending community clinics would usually have longer waiting times than when they see a private dentist. While community clinics would be cheaper than the private dentists, community clinics usually have a cut-off time or patient quota, after which patients are not seen, even if they have been waiting for some time. Patients might prefer private clinics because they can be seen all day and usually well into the evening after working hours, and because treatment could be more personalised. Many other factors are also important in the decision to have private rather than public treatment. Some of these revolve around easier access and reduced travelling time, which make visits less expensive than going to clinics further afield. Having to care for infants and children would be another consideration. That many patients choose private, oral clinics argues strongly for greater involvement and inclusion of the private dentists in HIV oral health programs, which could contribute to improved services to HIV positive persons. Further investigation and enhancement of the role of these practitioners appears warranted.

5.5 Needs

The results suggest that HIV positive patients have considerable needs across all six domains. Consistent with other research findings, these results show that health information, psychological and support needs ranked the highest of all the domains, with physical needs rating the lowest. This corresponds to work with cancer patients in Australia,⁵² and suggests common findings across diseases and care systems in different countries.

On all 28 items, at least 25% of the sample rated moderate or high needs. On 15 items at least half the sample rated moderate or high needs. All six items of the informational domain were in the top ten needs with the three highest ranked items being the need for information about disability grants, the need for information about mouth diseases and the need for information so as to recognise simple diseases. Clearly, health information is a domain on which most need is indicated. The females scored significantly higher than the males on the informational domain but on no other domain except for a nonsignificant trend on socio-economic needs. The analyses therefore only partially supports the premise that females would experience greater need than males across a number of domains.

It is not surprising that more women scored higher on informational needs. This is consistent with other African studies which show similar results and is in keeping with the fact that since more women than men would be uneducated, illiterate and isolated at home, they would experience a greater need for information. Given the general level of poverty and high need for socio-economic items, one can easily accept patients high need for more information about disability grants, which ranked as the highest need. However, presentation bias could be involved in the reported need for information concerning oral diseases which was ranked as the second highest overall need. Maybe the fact that patients had been answering questions regarding oral health focused them on these issues. But, since 68% patients reported currently experiencing mouth problems, this bias could be minimal.

Psychological needs, despite appearing among the top ten needs, also appeared to be under-reported. In reviewing the diaries which were kept by the candidate and research assistants, it can be shown that during the sessions, many patients expressed a high degree of tenseness and unease and that many patients became highly emotional at the end of the session. Some patients used the opportunity to release pent up emotions, feelings, questions and to talk at length. It became evident that issues of disclosure and stigmatisation were not being adequately addressed, generally, that rejection and the fear of having to cope alone were major issues which patients were not sufficiently voicing. This was partly due to the shortage of available social workers and psychologists for counselling. These pent up, hidden, unresolved emotions and feelings which patients harboured, could be further detrimental to their already compromised health. However, in keeping with Maslow's hierarchy of needs, it could also be that the more basic needs of patients were so overwhelming that those concerns dominated their thoughts and actions to a greater extent than higher psychological needs.⁶⁹ Nevertheless, the importance of obtaining some resolution for the patients' psychological concerns cannot be under-estimated or left unaddressed.

Clearly there are many needs and the health care systems' capacity to address them may be stretched. It is important to consider alternative models of providing care and support such as home care and the greater inclusion of the church in caring. The diaries of the candidate and fieldworkers, as well as other worldwide research findings in relation to the role of the church suggest that HIV positive patients in Cape Town seek a positive, tangible form of assistance from their church organisations. In Woelk's article, over 80% of the patients desired more food or food supplements and 50% requested painkillers. Money was also strongly requested, probably reflecting the need for school fees, food, medicine and other pressing house-hold expenditures.⁷⁰ Similarly, in this study, when patients were asked at the end of the interview for comments, many requested material assistance such as clothing and assistance for family members. This has implications for considering a wider role which such organisations could potentially have in the care and support of HIV positive patients.

While the age of patients did not influence their need level, their current symptom level did. The symptomatic group expressed higher needs than the asymptomatic group on four of the six factors, namely, socio-economic, psychological, support and informational domains. As can be expected, needs will increase and intensify as the disease progresses. HIV is not a static disease, it changes

over time, HIV patients' needs are also changing with time and many patients have many levels of unmet needs that are not adequately addressed by the existing health system. Continuous assessment of patients' needs appear to be necessary in order to achieve a more effective health delivery system which benefits the patient and the health system. This argues very strongly for effective usage of existing health facilities and systems as well as appropriate, early treatment and programs for those in the early symptomatic stages, so that the burden of the disease can be minimised.

5.6 Conclusion and recommendations

There is a need for the health system to meet the needs of HIV positive patients better. The oral findings suggest that many patients have symptoms but have not had adequate oral health instruction. The findings in the need section suggest that the need for instruction, not just in oral matters but across a broad spectrum of life-domains, is necessary. There is a strong need for the health system to better provide HIV positive patients with information regarding a range of issues. The domain of psychological need and the issues of disclosure, stigmatisation and counselling also require priority attention. The level of need among HIV positive patients is not uniform, and varies according to gender and symptom level. Females and those experiencing symptoms express greater needs. Sensitivity to this is important if health programs for HIV positive persons are to succeed. Structural and societal changes in issues relating to gender equality, increased literacy levels, greater access to education and health facilities, especially for women, are changes which need to be accelerated and more effectively implemented in South Africa today. These issues are being addressed presently but methodology, implementation and sustainability in those areas need more rigorous attention.

Some of the ways which could improve the system are as follows:

- 1. Greater involvement and inclusion of the private oral practitioner in HIV oral health preventive programs.**

- The private oral practitioner, working in collaboration with others in the health sector, could develop integrative, community and family orientated programs to investigate ways to diagnose and treat HIV related oral symptoms earlier and more effectively.
- These programs could include examining ways of improving patients oral knowledge, promoting oral, self-examination, and self-treatment methods for simple, minor oral symptoms.
- There could be a greater contribution by the general oral practitioner in oral matters for home-carers of persons with HIV/AIDS. This could be achieved partially through the examination of training and re-education of oral health professionals with regard to HIV positive patients, the production of education modules, treatment guidelines and protocols for oral home-care and their patients.

2. Greater inclusion of the churches and some of its members in caring and support programs for HIV positive patients.

- Such inclusion could be beneficial to society in many ways. Many skills and resources, if employed creatively and carefully, could prove beneficial to the HIV positive patients and the community. Such an approach would be complementary to our current policies of reconstruction and development.

3. Provision of selective care, counselling, education and information across a broad spectrum of relevant need issues for HIV positive persons by health workers from the traditional and the alternative or non-traditional health systems.

- This could be facilitated through the use of integrated, community and family orientated outreach and prevention programs.

- Programs should be creative and innovative, using realistic, feasible guidelines and protocols for reaching the HIV positive patients and the community. The patients and the community would also be involved in the creation and dissemination of such programs.
- The issues of disclosure, stigmatisation and ignorance about HIV matters should be given priority in these outreach programs.
- Existing clinics and health care facilities dealing with HIV positive patients should re-examine their care, particularly towards enhancing the capacity to provide patients with information.

4. **Repeated or periodic needs assessment to see if change has occurred or whether the system is meeting the needs of HIV positive patients should be initiated.**

- Those involved in research could assist in this process by contributing to the development of user-friendly, simple, cheap, valid and reliable assessment instruments for different risk groups.
- A picture rather than a word orientated instrument for groups of people with high levels of illiteracy could also be considered and developed.

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INFORMATION AND CONSENT FORM
LETTER TO PATIENTS FROM RESEARCHER

Dear Sir/Madame/Mrs/Mr/Miss/Ms

I am from the University of the Western Cape and my name is Cecily Camara. We are conducting a study to assess the needs of HIV positive persons. The project also looks at problems patients might have with their mouths.

Information from the study will help us to develop better services and care for people like you. One particular area we are looking at is how HIV positive persons and their carers can care for themselves at home. Such a programme is already being tried out but it does not include mouth care. We would like to include the section on mouth care and possibly other sections which have not been included such as coping strategies for certain stressful situations and providing information which patients might need for emergencies and self-care.

If you agree to participate you can either fill in the questionnaire yourself or answer the questions which we will ask. You may choose to speak or write in English, Xhosa or Afrikaans. You will be given an opportunity to ask questions at the end of the interview and can be assured that all matters regarding this research will be confidential. The questionnaire will take about 20 minutes to complete.

If you are willing to assist, could you kindly complete the bottom section. Further information about the research can be obtained from the researcher, C. Camara, on (021) 938-0438. Your help is greatly appreciated.

Yours faithfully
C. Camara

University of the Western Cape
Dental Faculty
Mitchells Plain

(Please tick in the box)

Yes, I wish to take part in this study

No, I do not wish to take part in this study

PERMISSION FORM FOR CHILDREN UNDER 16 YEARS OF AGE

Dear Parent/Guardian

Your daughter/son will be coming to the outpatient clinic on _____.

We would like to ask your permission to allow _____ to participate in this research by filling in a questionnaire.

If there are matters you would like to clarify, you can contact the researcher at the number given below.

Your co-operation is appreciated. The information gathered from the questionnaires will assist us to develop programmes which will benefit all patients.

Yours faithfully



C. Camara

Tel No.: (021) 938-0438

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YES, MY SON/DAUGHTER _____ CAN PARTICIPATE

NO, MY SON/DAUGHTER _____ CANNOT PARTICIPATE

Please tick the appropriate box.

NEEDS QUESTIONNAIRE

THIS IS A QUESTIONNAIRE ABOUT THE NEEDS OF HIV POSITIVE PATIENTS

WHY WE NEED YOUR HELP

For most people, the experience of being HIV positive brings with it many changes. We are concerned that patients may be left to cope alone with some problems that can arise in different life areas. We would like you to help us identify the problems you have experienced so that we can help to plan better services and care for people with HIV infection.

HOW YOU CAN HELP US

1. Please read through the instructions on the following page carefully.
2. Please respond to all questions. Do not skip any items or leave any questions blank.
3. There are no right or wrong responses. We are interested in your honest views.
4. When you have finished simply hand the questionnaire to the research person.

CONFIDENTIALITY

Names and addresses are not required. All information regarding this research is confidential, locked away and access is only possible for the researcher and supervisors. All information in paper form relating to this research will be shredded as soon as the data is analysed.

ANY PROBLEMS

If you have any questions or concerns, please telephone Ms C. Camara at the Medical Research Council, telephone 9380438 or 9380453.

HELP WITH THE QUESTIONNAIRE

If you need someone to help you fill in the questionnaire the researcher and the assistant are available. Between them they speak English, Xhosa and Afrikaans.

OFFICE USE ONLY			
DATE	<input style="width: 100%;" type="text"/>	RESEARCHER/ASSISTANT ID.	<input style="width: 100%;" type="text"/>
CLINIC/HOSPITAL	<input style="width: 100%;" type="text"/>	NUMBER	<input style="width: 100%;" type="text"/>

INSTRUCTIONS

There are 3 sections to the questionnaire. Kindly answer all sections and all questions. Some require a response of a few words. Others require circling a number, for example

SECTION A

(Please circle one number)

1. Are you:

Male

1

Female

2

2. Are you:

married/living together

1

divorced/separated

2

widow/widower

3

single/never married

4

3. How many children do you have?
(Please write on the line)

4. Do you have children who are
(Circle a number/s)

under 5 years

1

between 6-11 years

2

between 12-17 years

3

older

4

5. **What is your home language?**

Afrikaans 1

English 2

Xhosa 3

Other
(please specify) _____ 4

6. **Do you describe yourself as being any of these listed below?**
(You do not have to answer if you so desire)

White 1

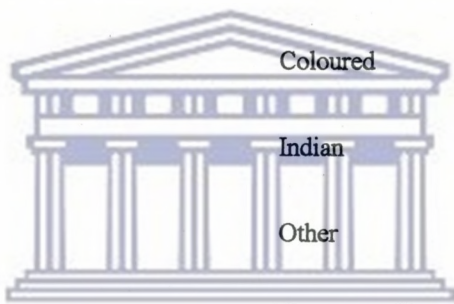
African 2

Coloured 3

Indian 4

Other 5

Please specify _____ 6



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7. **Where do you usually live?**

on a farm 1

in a city 2

in a rural area 3

in a squatter camp 4

other 5

8. **How many people besides yourself are living at your address?**
(Please write on the line) _____

--	--

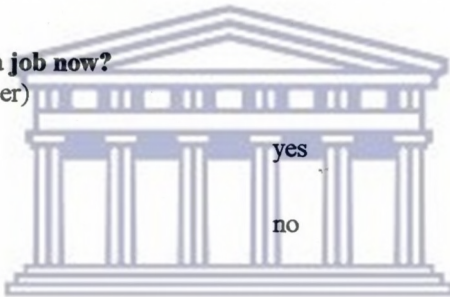
9. **How old were you on your last birthday?**
(Please write on the line) _____ years

--	--

10. **What is the highest school standard that you have completed?**
(Circle one number)

- never attended school 1
- Standard 2 (primary school) 2
- Standard 6 (high school) 3
- Standard 8 (high school) 4
- Standard 10 (high school) 5
- University 6

11. **Do you have a job now?**
(Circle a number)



- yes 1
- no 2

12. **What work did you do?**
(Please write on the line)

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13. **What is your family income?**

- less than R300 per month 1
- between R300-500 per month 2
- between R500-1000 per month 3
- between R1000-2000 per month 4
- more than R2000 per month 5
- other _____ 6

14. How much help do you get in the home from the following people?
(Circle the 4 if those persons do not live with you)

	no help	some help	lots of help	does not live here
husband/wife	1	2	3	4
children	1	2	3	4
sister/brother	1	2	3	4
aunt/uncle	1	2	3	4
mother/father	1	2	3	4
other (please specify)	1	2	3	4

15. Do you belong to any of the following?
(Circle those you belong to)

	Yes	No
a civic organisation	1	2
a church body	1	2
a sport organisation	1	2
an educational body	1	2
a music group	1	2
a community organisation	1	2
a health organisation	1	2
a social group (play cars/go out together)	1	2

SECTION B

For each item indicate whether you needed help with this as a result of being HIV positive. Place a circle around the ONE number under the heading that best describes whether you needed help with this. There are 4 possible responses to choose from.

No need for help

No. 1 = not applicable

This item has not been a problem for you as a result of being HIV positive.

Some need for help

No. 2 = low need for help

The item is of little concern, causing little physical, emotional or social problems. Your need for help is low and you are generally satisfied.

Moderate need for help

No. 3 = The item caused you some concern or discomfort. You have a moderate need for additional help with the problem or issue now.

Great need for help

No. 4. = The item is of major concern or importance to you. You have a strong need for additional help with the problem or issue.

Do you need:

	no need	low need	moderate need	great need	
1. more support from friends	1	2	3	4	<input type="checkbox"/>
2. more support from family	1	2	3	4	<input type="checkbox"/>
3. more support and contact from community organisation/s	1	2	3	4	<input type="checkbox"/>
4. exercise more	1	2	3	4	<input type="checkbox"/>
5. to get out more often	1	2	3	4	<input type="checkbox"/>
6. to take more care of yourself	1	2	3	4	<input type="checkbox"/>
7. to improve your reading	1	2	3	4	<input type="checkbox"/>
8. to improve your writing	1	2	3	4	<input type="checkbox"/>
9. tap water in the home	1	2	3	4	<input type="checkbox"/>
10. electricity in the home	1	2	3	4	<input type="checkbox"/>
11. a job which you can do at home	1	2	3	4	<input type="checkbox"/>
12. some (nursing) home-care	1	2	3	4	<input type="checkbox"/>
13. help with taking medicine	1	2	3	4	<input type="checkbox"/>
14. more energy to take care of yourself	1	2	3	4	<input type="checkbox"/>
15. false teeth	1	2	3	4	<input type="checkbox"/>
16. to get rid of bad breath	1	2	3	4	<input type="checkbox"/>
17. relief from pain in the mouth and face area	1	2	3	4	<input type="checkbox"/>
18. help in coping with stress due to illness	1	2	3	4	<input type="checkbox"/>
19. help in coping with sleepless nights	1	2	3	4	<input type="checkbox"/>
20. help in coping with fears about being left alone	1	2	3	4	<input type="checkbox"/>

	no need	low need	moderate need	great need	
21. help in coping with sexual problems e.g. partner not interested	1	2	3	4	<input type="checkbox"/>
22. help with trying to stop smoking	1	2	3	4	<input type="checkbox"/>
23. help with trying to stop drinking	1	2	3	4	<input type="checkbox"/>
24. help in coping with difficult family relationships	1	2	3	4	<input type="checkbox"/>
25. help in talking to the family about being HIV pos	1	2	3	4	<input type="checkbox"/>
26. written information about how to handle your illness at home	1	2	3	4	<input type="checkbox"/>
27. to know how to recognise simple disease signs and symptoms	1	2	3	4	<input type="checkbox"/>
28. to have information about where to get emergency treatment and help	1	2	3	4	<input type="checkbox"/>
29. to have information about community resources/support groups e.g. safe houses	1	2	3	4	<input type="checkbox"/>
30. to have information about disability grants	1	2	3	4	<input type="checkbox"/>
31. to know about mouth diseases	1	2	3	4	<input type="checkbox"/>

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SECTION C

The following section concerns specific oral and medical questions.

1. **Have you had any of the following problems?**
(Please circle 2 numbers for each symptom to say whether you had the symptom before your HIV was diagnosed and whether you had the symptom after the HIV was diagnosed)

	BEFORE HIV was diagnosed		AFTER HIV was diagnosed		
	YES	NO	YES	NO	
bleeding gums	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
rotten teeth	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
mouth ulcers (sores)	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
loose teeth	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
pain	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
bad breath	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
swollen gums	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
red gums	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
white, furry tongue	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
chewing problems	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
plaque (white/yellow food and germs on teeth)	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
calculus (hardened plaque)	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
stains	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
other (please specify)	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>

2. **For the conditions you mentioned, how bad were they?**
 (mild = 1, moderate = 2, severe = 3, not applicable (N/A) = 4)

	mild	moderate	severe	N/A	
bleeding gums	1	2	3	4	<input type="checkbox"/>
rotten teeth	1	2	3	4	<input type="checkbox"/>
sores in the mouth	1	2	3	4	<input type="checkbox"/>
loose teeth	1	2	3	4	<input type="checkbox"/>
pain	1	2	3	4	<input type="checkbox"/>
very bad breath	1	2	3	4	<input type="checkbox"/>
swollen gums	1	2	3	4	<input type="checkbox"/>
red gums	1	2	3	4	<input type="checkbox"/>
white, furry tongue	1	2	3	4	<input type="checkbox"/>
chewing problems	1	2	3	4	<input type="checkbox"/>
plaque	1	2	3	4	<input type="checkbox"/>
calculus	1	2	3	4	<input type="checkbox"/>
stains	1	2	3	4	<input type="checkbox"/>
other (please specify)	1	2	3	4	<input type="checkbox"/>



3. Did you have any of the following treatment?

	BEFORE HIV was diagnosed		AFTER HIV was diagnosed		
	YES	NO	YES	NO	
some-one telling you how to look after your mouth	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
teeth being cleaned	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
teeth pulled out	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
fillings	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
other (please specify)	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>

4.a. When did you first have any problems with your mouth?

within the last three months 1

3-6 months ago 2

6-12 months ago 3

1-2 years ago 4

2-3 years ago 5

3-5 years ago 6

more than 5 years ago 7

4.b. Do you still have problems with your mouth?

yes 1

no 2

5. **Apart from being diagnosed HIV positive, do/did you have any of the following problems/procedures?** (Circle a number in both columns)

	BEFORE HIV was diagnosed		AFTER HIV was diagnosed		
	YES	NO	YES	NO	
diabetes	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
epilepsy	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
heart diseases	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
tuberculosis	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
sexual diseases e.g. gonorrhoea	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
surgery (operation)	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>
other (please specify)	1	2	1	2	<input type="checkbox"/> <input type="checkbox"/>

6. **What medications do/did you take?**
(Please write on the lines)

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7. **How long ago were you diagnosed HIV positive?**
(Circle one number only please)

- | | |
|------------------------------|---|
| within the last three months | 1 |
| 3-6 months ago | 2 |
| 6-12 months ago | 3 |
| 1-2 years ago | 4 |
| 2-3 years ago | 5 |
| 3-5 years ago | 6 |
| more than 5 years ago | 7 |

8. Do you presently experience any of the following?

	YES	NO	
tiredness	1	2	<input type="checkbox"/>
chest problems	1	2	<input type="checkbox"/>
weight loss	1	2	<input type="checkbox"/>
nausea	1	2	<input type="checkbox"/>
diarrhoea	1	2	<input type="checkbox"/>
skin rashes	1	2	<input type="checkbox"/>
swellings	1	2	<input type="checkbox"/>
fevers	1	2	<input type="checkbox"/>
infections	1	2	<input type="checkbox"/>



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9. Do you think that you can do things to help to manage your illness?

Yes	No
1	2

10. How many times have you had to live away from home to attend treatment?

never	1
once	2
twice	3
more than twice	4

11. Do you agree with the following statements?
(Circle a number for each part)

	YES	NO	
a. germs and food should be brushed off the teeth everyday	1	2	<input type="checkbox"/>
b. blood on your toothbrush when you brush is a sign of disease	1	2	<input type="checkbox"/>
c. finding out early about disease can keep one healthy for longer	1	2	<input type="checkbox"/>

12. **How often do you brush your teeth?**
(Circle one number)

- | | | |
|--|---|--------------------------|
| never | 1 | |
| occasionally (less than once a week) | 2 | |
| several times a week (but not every day) | 3 | |
| once a day | 4 | |
| more than once a day | 5 | <input type="checkbox"/> |

13.a. **Do you have any of the following?**

- | | | |
|------------------------|---|--------------------------|
| no teeth of your own | 1 | |
| some of your own teeth | 2 | |
| most of your own teeth | 3 | <input type="checkbox"/> |
| all of your own teeth | 4 | |

13.b. **Do you have:**

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- | | | |
|-----------------------------|---|--------------------------|
| upper and lower false teeth | 5 | |
| lower false teeth | 6 | <input type="checkbox"/> |
| upper false teeth | 7 | |

14. **If you have a broken tooth, what are you most likely to do?**

- | | YES | NO | |
|------------------------------|-----|----|--------------------------|
| go to the hospital | 1 | 2 | <input type="checkbox"/> |
| go to the clinic | 1 | 2 | <input type="checkbox"/> |
| go to the community nurse | 1 | 2 | <input type="checkbox"/> |
| go to the traditional healer | 1 | 2 | <input type="checkbox"/> |
| go to the private dentist | 1 | 2 | <input type="checkbox"/> |
| other (specify) | 1 | 2 | <input type="checkbox"/> |

15. **If you have any mouth problems such as rotten teeth or bleeding gums, how concerned would you be about it?**
(Circle one number only)

unconcerned 1

concerned 2

very concerned 3

16. **Finally, could you say what is most important in your life at this moment in time?**

1. _____

2. _____

3. _____

4. _____

5. _____



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YOU HAVE NOW FINISHED THIS QUESTIONNAIRE!

WESTERN CAPE

17. **Are there any comments you wish to make? If so, space is provided just below for your comments**

Kindly hand this questionnaire to the researcher.

Thank you for taking the time to fill in the questionnaire.

If you wish to contact the researcher (C. Camara) she is available on line 938-0438.

FACTOR ANALYSIS RESULTS

1. Socio-economic factor	commonalities	eigenvalues
- need to improve your writing	0.5940	0.755
- need for tap water in the home	0.6326	0.709
- need to improve your reading	0.6265	0.678
- need for electricity in the home	0.6596	0.625
- need for some nursing home-care	0.5155	0.568
- need to take better care of yourself	0.5639	0.465
- need for a job which can be done at	0.4398	0.490

Total variance explained by the factor = 3.302

2. Informational factor	commonalities	eigenvalues
- need to know about mouth disease	0.5533	0.722
- need to have information about disability grants	0.4744	0.701
- need to have information about where to get emergency treatment and help	0.5559	0.642
- need to have information about community resources/support groups	0.5914	0.633
- need to know how to recognise disease signs and symptoms	0.4878	0.552
- need to have written information about how to handle your illness at home	0.4573	0.515

Total variance explained by the factor = 3.073

3. Psychological factor	commonalities	eigenvalues
- need help in trying to stop drinking	0.6494	0.840
- need help in trying to stop smoking	0.6136	0.802
- need help in coping with difficult family relationships	0.5558	0.624
- need help in talking to the family about being HIV+	0.4852	0.468
- need help in coping with fears being left alone	0.4553	0.459

Total variance explained by the factor = 2.639

4. Medical and oral factor	commonalities	eigenvalues
- need more energy for self-care	0.5765	0.602
- need relief from pain in the mouth and face area	0.5434	0.554
- need to get rid of bad breath	0.5377	0.546
- need false teeth	0.3645	0.526
- need help in coping with stress due to the illness	0.5706	0.486
- help in coping with sleepless nights	0.5289	0.454

Total variance explained by the factor = 2.196

5. Social support factor	commonalities	eigenvalues
- need more support from friends	0.6839	0.828
- need more support from community	0.6445	0.794
- need more support from family	0.6780	0.761

Total variance explained by the factor = 2.172

6. Physical factor	commonalities	eigenvalues
- need to exercise more	0.7057	0.810
- need to get out more often	0.6059	0.750

Total variance explained by the factor = 1.710

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