ORAL MANIFESTATIONS OF HIV INFECTION

Implications for the Delivery of Oral Health Care Services

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I declare that this thesis is my original work and has not been submitted for any other degree to any other institution. The sources I have quoted have been acknowledged by means of references

Signed .....
N Shaikh

Abstract

The prevalence and determinants of oral lesions related to Human Immunodeficiency Virus (HIV) infection were examined in the context of the delivery of oral health care services. This was complemented by an examination of the perceptions and experiences of oral health workers and HIV infected patients with regard to oral health care services.

Method: A cross-sectional study was carried out on 239 patients who attended a HIV-outpatient clinic. Participants' dental history and perceptions were determined through structured interviews, whilst clinical and medical details were obtained from physical examinations and clinical records. A qualitative study of oral health care workers was carried out to assess their perceptions and experiences with regard to service provision. A costing exercise was done to determine the average cost of care per visit. **Results**: Oral HIV lesions presented in 68.6% of the sample. Significant determinants of oral lesions presence included, CD4 cell counts <200 (OR 2.07), smoking (OR 2.77), presence of calculus (OR 4.27) and poor access to oral care (OR 6.36). The majority of the patients sought dental care from the public sector services (67%) and the prime reason was for emergency care (70%). The main barriers to care from the patient perspective were cost (33%), fear of pain (21%) and rejection (16%). The majority (87%) of the oral health care workers were in favour of providing comprehensive care at primary level. The main concerns of the oral health care providers were the management of needle-stick injuries and their skills deficiency in managing complex cases. The average cost of care per visit was R130.73.

Conclusion: Oral lesions presented in more than two thirds of the sample. Barriers to care, lowered immune status, smoking and high calculus deposits were significantly associated with the presence of lesions. The most commonly reported barriers to seeking care were cost and fear of pain. Patients' perception of oral health and their health seeking behaviour were influenced by oral symptoms. The rising cost of treating oral lesions will impact on the delivery of health care services. Oral morbidity related to HIV infection can be reduced with the application of simple preventative, health promotive measures such as promoting smoking cessation and good oral hygiene, removal of local tooth deposits and improved access to health services.

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CHAPTER ONE: INTRODUCTION

1.1. Introduction

The Human Immunodeficiency Virus (HIV) epidemic continues to be a serious public health concern in South Africa (SA). South Africa is considered to have the fastest growing epidemic in the world, with an estimated prevalence of infection ranging from 7.1% to 32.5% in 1999 (Department of National Health 2000). By the end of 1998, 4 million South Africans were estimated to be HIV-infected (UNAIDS, 1998). The consequence of the rapidly growing HIV epidemic in SA is the rise in HIV-related morbidity, resulting in an increased demand for health-care.

The oral health sector is faced with challenges of providing care for those afflicted by the disease and contributing to the surveillance of Human Immunodeficiency Virus (HIV) /Acquired Immune Deficiency Syndrome (AIDS). It is well established that HIV-infected persons present with oral lesions at various stages of the disease (Greenspan *et al.* 1992). Studies examining the natural history of HIV infection show that oral lesions present in 60-70% of HIV-infected persons at some stage of their disease (Lamster *et al.* 1994, Nittayananta & Chungpanich 1997; Arendorf *et al.* 1998). With the increasing prevalence of HIV infection in South Africa, it is anticipated that the number of HIV-infected persons seeking oral health care in SA will increase. For example, on the basis of 4 million persons infected with HIV disease, it is estimated that 2.4 to 2.8 million persons would present with oral lesions, assuming a prevalence of 60-70% for oral HIV-lesions. This will have major implications on the delivery of services and the allocation of resources. The purpose of this study is to examine HIV-related oral lesions in a South African cohort from a public health service delivery perspective. This information will be useful for the provision, planning and implementation of appropriate oral health services for HIV-infected persons.

From the early phase of the epidemic, researchers focused mainly on the clinical manifestations of oral HIV-lesions. More recently, there has been a global shift from descriptive analysis of oral HIV-lesions to examination of the determinants of oral HIV-related morbidity. The clinical manifestations of oral HIV-related lesions are closely linked to the immunologic status of the patient, socio-demographic and environmental

factors such as sexual identity, socio-economic status, smoking and drug intake (Lamster *et al.* 1994; Coates *et al.* 1996). In South Africa, there is an absence of such analyses in the area of oral HIV care. The purpose of this study therefore, is to examine the clinical features of oral HIV-lesions in relation to the determinants of disease in a group of hospital attenders in the Western Cape Province.

An understanding of the clinical presentations and contributory factors of oral HIV-related lesions is important, as early detection and treatment can act at three levels. Firstly, at a preventative level, it may facilitate early screening of oral HIV-related lesions. Secondly, at a curative level, it may improve the quality of life of those affected with the application of simple and inexpensive therapeutic measures. Finally, it could provide information for the planning and development of appropriate oral health services for HIV-infected individuals.

Oral health care for HIV-infected persons in the public health sector in SA, is provided mainly at the academic institutions, secondary hospitals and primary health services. There are no formal dedicated oral-HIV care centres. The need to examine the HIV epidemic in the context of the broader health reform strategies is important for oral health care providers and planners in order to offer comprehensive health services and improve access to health care. This will enable the development of appropriate preventative and curative strategies for the delivery of oral health care.

There are a number of factors which influence access to care and utilisation of oral health services by HIV-infected persons. These include cost of care, fear, social stigma and socio-demographic characteristics of infected individuals and the attitudes of health-care provider (Mc Carthy, Haji & Mackie 1996; Camara 1996). A study examining South African oral health-care students' willingness to treat infected persons showed that 14% felt comfortable treating HIV positive persons (Tootla, Shaikh & Rahbeeni 1994). Another study of oral health students revealed that 84% preferred to refer their patients to a teaching hospital because of their perceived inability to treat HIV-infected patients appropriately (Shaikh, Hamekar & Moola 1998). Sixty eight percent of the participants perceived a high risk of contracting HIV infection with 76% reporting the fear of being infected through a needle-stick injury. Studies examining utilisation of services by HIV-infected persons in North America, New Zealand and South Africa showed that access to oral health-services was hindered because of the fear of discrimination, inability to afford care, or the fear of rejection

(Jacobson, Stocking & Gramelspacher 1989; Terry, Jones & Brown 1994; Camara 1996). These are important factors that influence the delivery of appropriate and accessible oral HIV care. In South Africa, few studies have examined the HIV-patient's perspective of oral health care services. A study examining the perceived needs of HIV-infected persons in South Africa revealed that many patients reported unmet needs that are not being effectively addressed by the existing health services (Camara 1996). This study therefore, examined the oral HIV-related morbidity and the service utilisation of oral health services by HIV-infected persons.

1.2. Significance and Background

Discussions with researchers working in the area of HIV/AIDS and health care providers of HIV patients at the larger outpatient hospitals and clinics in the Western Cape Province, confirmed the need to study the oral problems associated with HIV infection for the following reasons:

- More information on oral lesions in relation to the changing immune status in Africa is needed, as these lesions may serve as early markers in the various stages of disease progression.
- There is a need to link oral HIV-related morbidity to the broader determinants of the diseases such as socio-demographic, health status and environmental factors.
- The HIV-infected patients' oral health experience needed to be examined in relation to the delivery of oral health care.
- Patients presenting with oral symptoms are often not thoroughly evaluated, as a limited number of examiners are sufficiently trained in diagnosing oral soft tissue changes.
- An improved oral health service for the treatment of oral problems amongst HIV-patients needs to be established.
- A multidisciplinary approach in HIV/AIDS research and in the delivery of health care is essential for meaningful results. An oral health component would add depth to the existing medical cohort study that was being carried out at Groote Schuur Hospital.

The above factors are important for the delivery of accessible and appropriate health services. Groote-Schuur Hospital (GSH), in the Western Cape Province, serves a large HIV positive cohort. This includes heterosexual and homosexual adults and inmates from Pollsmoor prison. There are no formal, dedicated oral health services for these patients. Most patients are referred to private practitioners or to the public

health institutions in a random manner. The need to introduce an oral health component to the existing medical care is appropriate to provide a more comprehensive and multidisciplinary service. The results of this study may contribute to a better understanding and delivery of oral health care for HIV-infected persons at this site. This information may be useful for the planning of appropriate treatment guidelines and protocols for care of these patients. It would also be useful for educational purposes as it is argued that most medical personnel are not adequately trained in oral diagnosis, which often results in misdiagnosis, inappropriate care or the loss of opportunity to intervene. A study comparing the oral diagnostic skills of physicians with those of oral clinicians showed significant differences in their diagnosis (Cruz *et al.* 1996). Distinguishing between the various types of oral lesions and a thorough evaluation is important as this impacts on appropriate management of HIV-infected patients (Dodd *et al.* 1991).

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter reviews the literature on oral lesions in HIV-infected individuals. It examines the significance, presentation and the determinants of oral lesions in HIV-positive persons. The delivery of oral care for HIV-infected individuals is also examined from the patient and provider perspective. Finally, the financial implications of treating these lesions is discussed from a provider perspective.

2.2. The Prevalence of HIV Infection in South Africa

The pattern[1] of the HIV epidemic in SA in the early 1980's, was in many respects similar to that observed in North America and Europe two decades ago (Whiteside 1993). This was followed by a demographic transition of the HIV epidemic, manifesting as a shift from homosexual men (pattern I) to heterosexual individuals (pattern II) from the lower economic sector, as the epidemic progressed (Whiteside 1993; Ledergerber *et al.* 1998).

The national prevalence of 2.9% measured in 1992, rose exponentially to 23.6 % in 1999 (Department of National Health 2000). The Western Cape Province has a prevalence of 7.12%, which is the lowest in the country, although the rates have been doubling steadily over the last few years (Department of National Health 2000). However, within the province there are areas with a high prevalence of HIV infection such as Khayelitsha (14.4%) and Guguletu (13.28%) (Department of National Health 1999).[2] These are considered conservative estimates of the magnitude of the HIV problem in SA, as these rates are derived from the national antenatal sentinel surveys at public health services. The increasing burden of this epidemic necessitates urgent public health interventions and the provision of health care to a growing number of individuals (Kinghorn *et al.* 1996).

[1] There are different patterns of spread HIV namely pattern I , II and III. Pattern I is more common in Western Europe and Northern America, pattern II in Sub-Saharan Africa and pattern III in Asia, Middle East, North Africa and Eastern Europe. Latin America has combination of I and II.

[2] At the time is writing this document, the intra-provincial figures for the Western Cape for the year 1999 were not available.

2.3. The Oral Health Perspective

The oral health sector is faced with a challenge of providing care to HIV-infected persons, since oral lesions present at various stages of HIV/AIDS disease and manifest in approximately 60-80% of the infected population (Nittayananta & Chungpanich 1997; Arendorf *et al.* 1998). The rapidly increasing prevalence of HIV infection, together with an increased demand for oral HIV-related care in South Africa will impact on the delivery of oral health services in the already overburdened public health sector. Oral Health Care Workers (OHCW) and policy makers of health care services are therefore expected to play a significant role in the delivery of appropriate and accessible health services.

2.4. The Prevalence of Oral Lesions

A wide range of opportunistic infections (bacterial, viral and fungal), many of which manifest intra-orally, are characteristic manifestations of HIV infections (Schiódt *et al.* 1990; Greenspan *et al.* 1992). The prevalence of HIV-related oral lesions reported in the literature varies considerably (Table 1).

In Africa, several studies have reported the occurrence of HIV-related oral lesions with the prevalence ranging from 15% to 92% (Wanzala *et al.* 1989; Maresky 1996; Itula *et al.* 1997; Arendorf *et al.* 1998, Jonsson *et al.* 1998). These differences may be attributed to the adoption of different methodological criteria in the studies describing the oral manifestations of HIV infection. These include factors such as sample selection, the application of varying definitions for lesion diagnosis, socio-economic and demographic. In South Africa, the prevalence of oral lesions is reported to range from 60.4% to 90% (Maresky 1996; Arendorf *et al.* 1998).

2.5. The Determinants of Oral HIV-lesions

The manifestation of oral HIV-related lesions have been reported to vary according to different cohorts and settings (Lamster *et al.* 1994; Palmer *et al.* 1996; Patton, McKaig & Eron 1998). Certain factors such as variation in the strain of the virus, environmental conditions, socio-economic status, access to medical care, sexual orientation and ethnic groups have been reported to contribute to varying patterns of disease (Robinson *et al.* 1997; Patton, McKaig & Eron 1998).

Table 1. The Prevalence of Oral Lesions in Adult Population Groups with HIV infection

Reference	Site	Prevalence	Study Sample size	Sample	Analysis
Arendorf *et al.* 1998	South Africa	60.4%	Cross sectional 600	Hospital Attenders	Prevalence by different groups
Maresky 1996	South Africa	90%	Cross sectional 61	Oral Medicine Clinic Attenders	Prevalence and clinical features
Matee, Scheutz & Moshy 2000	Tanzania	HIV 10% AIDS 37%	Cross Sectional 192	HIV positive and Negative Adults	Prevalence and determinants of lesions
Jonsson *et al.* 1998	Zimbabwe	92%	Prospective 100	Hospital Attenders	Prevalence and clinical features
Hodgson. 1997	Zambia	40.2%	Cross sectional 107	Hospital Attenders	Prevalence, positive predictive values of oral lesions
Wanzala *et al.* 1989	Kenya	15.6%	Prospective 269	HIV-positive Women	Prevalence of lesions and survival analysis
Itula *et al.* 1997	Namibia	20.6%	Cross sectional 405	Dental Clinic Attenders	Prevalence of oral lesions and serological tests
Lamster *et al.* 1994	USA	64%.	Cross sectional 160	Intravenous drug users and Homosexuals	Prevalence and determinants with adjustment for variables
Nittayananta & Chungpanich 1997	Thailand	71 %	Cross sectional 124	Hospital Attenders	Prevalence of lesions by gender with adjustment for variables excluding CD4

Studies carried out in East Africa report differences in the oral presentation compared to that found in North America and Europe (Wanzala *et al.*1989; Hodgson 1997). These studies showed that oral candidiasis was the most prevalent type of lesion observed in the African cohorts whilst hairy leukoplakia in the European and American cohorts (Wanzala *et al.* 1989; Lamster *et al.* 1994; Hodgson 1997; Arendorf *et al.* 1998). The differences in the prevalence of hairy leukoplakia have been explained by the variation in the profile of the cohorts namely, predominantly heterosexual groups in Africa and homosexual men in the developed countries. The variation in oral disease manifestation may be attributed to different transmission patterns of HIV disease in various cohorts, malnutrition, use of medications, concurrent systemic diseases such as tuberculosis and sexual behaviour (Soubry *et al.* 1995; Hodgson 1997). A South African study examining inter-group differences by ethnicity, gender and sexual orientation showed varying patterns of oral manifestations by ethnic group (Arendorf *et al.* 1997). While the inter-group study showed different patterns of oral HIV lesion manifestation, namely variation in types of oral lesions, a notable limitation in the study design was the failure to control for confounding and modifying factors in the analysis of the data when making comparisons by ethnic group and sexual orientation. Studies showed that the confounding and

modifying factors included the link between access to health-care, ethnicity and socio-economic status; the presence of other diseases such as tuberculosis, smoking, intake of medications and basic oral hygiene (Wanzala *et al.* 1989; Lamster *et al.* 1994; Shiboski, Hilton & Neuhaus 1996; Ramirez-Amador *et al.* 1998). In Sub-Saharan Africa, limited studies have analysed the determinants of oral HIV-related lesions (Matee, Scheutz & Moshy 2000). The need to examine these factors are important as environmental factors may influence the occurrence of disease. For example, in the Western Cape, the presentation of AIDS is confounded by the tuberculosis epidemic. The prevalence of tuberculosis in the province is 699/100 000, which is one of the highest rates in the world (Department of Health 1999). This has influenced the clinical appearance of HIV disease as these infections are frequently observed as a complication of AIDS (Wood *et al.*1995). Similarly, the oral presentation of HIV disease may be altered due to the presence of tuberculosis. Tuberculosis therapy entails prolonged antibiotic intake and is known to exacerbate the occurrence of opportunistic fungal infections, such as candidiasis, which is characteristically seen in HIV-infected persons (Odds 1988). It is therefore necessary to account for the determinants of disease when describing the manifestations of HIV-related oral lesions.

2.6. The Role of Oral Lesions in the Management of HIV-infected Persons

The significance of studying oral HIV-lesions is clear as these lesions are known to be important landmarks of disease stage, prognostic indicators of the disease and have been used as criteria for the admission of patients into drug trials (Lamster *et al.* 1994). These lesions can be detected visually with minimal equipment and often present as the first and only presenting sign or symptom of the disease (Greenspan *et al.* 1992).

2.6.1. Oral Diseases as Early Features of Disease

Schiφdt *et al.* in 1990, indicated that oral HIV-lesions showed an 85% positive predictive value for HIV/AIDS in patients without prior knowledge of their HIV status. A study of a Greek cohort supported this finding, where the suspicion of infection was based on the presence of oral lesions (Laskaris, Hadjivassiliou & Stratgos 1992). Several studies have also shown that the presence of oral candidiasis is indicative of HIV sero conversion (Colebunders *et al.* 1991; Lifson *et al.* 1992). Oral HIV-related lesions are treatable with simple interventions, although, if untreated, may lead to severe pain, discomfort and loss of masticatory function. Oral health workers should therefore be knowledgeable and observant of these lesions as they can

play an important role in the early screening and staging of diseases, providing appropriate care and improving the quality of life of those afflicted by these lesions.

2.6.2. Oral Lesions as Predictors of Disease Progression

The relationship between the development of oral candidiasis, particularly the pseudomembranous form, has been linked to disease progression (Klein *et al.* 1984; Murray *et al.* 1985). A similar relationship was observed with oral hairy leukoplakia and the presence of AIDS (Greenspan, Greenspan & Conant 1984). The San Francisco cohort study of homosexual men showed that individuals with oral candidiasis or hairy leukoplakia were more likely to develop AIDS within six months compared to those without oral lesions (Greenspan 1997). This hypothesis was supported by subsequent studies where CD4 cell counts were controlled for in the analysis (Maden, Hopkins & Lafferty 1994; Clark *et al.* 1995).

2.6.3. Oral Lesions as Clinical Markers for Drug Trials

Oral candidiasis, hairy leukoplakia and herpes zoster have been used as markers of clinical disease progression in zidovudine trials (Fischl *et al.*1990; Kinloch-de Loes *et al.*1995). The incidence of these lesions were higher in the control group compared to the treated group, reflecting an alteration of disease progression with intervention. Oral lesions have also been used to determine entry and end-points in prophylactic intervention trials (Lamster *et al.* 1994).

2.6.4. Use of Oral lesions in Disease Classification and Staging

It is well established that certain oral lesions are used as important markers of disease stage and state (Greenspan *et al.* 1992). These lesions include oral candidiasis, oral hairy leukoplakia and Kaposi's sarcoma (Schulten, ten Kate & van der Waal 1990). The presence of these lesions form part of the clinical criteria for various disease classification systems for HIV/AIDS such as the World Health Organisation (WHO) Classification System and the Centres for Disease Control (CDC) Classification system (WHO 1990; Montaner *et al.* 1992; Centres for Disease Control 1993). Both the original and revised WHO Classification system uses oral lesions as criteria for disease staging. In fact, the above systems permit the use of oral candidiasis and hairy leukoplakia as signs of AIDS in place of HIV serology or CD4 cell counts, especially in settings where there are no laboratory facilities for serological assessment (Colebunders *et al.* 1987). The

1986 and 1993 Centres for Disease Control (CDC) AIDS surveillance systems take into consideration the presence of oral candidiasis, herpes zoster, hairy leukoplakia and persistent herpes simplex (CDC 1986; CDC 1993). The Walter Reed system on the other hand, places greater emphasis on oral candida and omits oral hairy leukoplakia (Redfield, Wright & Tramont 1986). The presence of oral candidiasis, herpes simplex and herpes zoster has been used as clinical criteria for staging paediatric HIV/AIDS (Galli *et al.* 1995). The pseudomembranous form of oral candidiasis has been shown to be a significant predictor of the development of *Pneumocystis carinii pneumonia*, after adjusting for CD4 cell counts (Kirby, Munoz & Detels 1994).

The above highlights that, for the successful and effective application of staging systems, health care workers need to be capable of diagnosing these lesions and treating them appropriately. Primary care physicians particularly, need to be knowledgeable of these lesions as they are most likely to encounter the lesions first in the clinical settings.

2.7. The Delivery of Oral Health Care to HIV-Infected Persons.

Individuals infected with HIV/AIDS in South Africa are largely from an impoverished sector of society, and therefore factors such as poor access to care, presence of tuberculosis and poor nutrition become relevant for the planning of health care services. Oral health care workers are faced with a number of challenges with regard to the provision of care for the growing number of HIV infected individuals. These include the need to practise universal precautions, to deliver optimal care and to ensure that services are accessible. In addition, oral health care workers are required to build links to other services as well as find methods of minimising levels of stress when treating these patients (Green 1997; Rudolph & Ogunbodede 1999).

In translating these challenges into specific health care delivery strategies, it is clear that aside from examining the implications of the epidemic from a biomedical perspective, where oral HIV-related lesions are clinically identified and treated, a wide range of service delivery issues need to be considered. Many of these are linked to broader health care delivery issues such as understanding the patient perspective with regard to their dental care experiences, examining provider perspective, determining access to oral health care services, exploring models of service delivery (dedicated or comprehensive), and assessing the cost implications of treating HIV-related oral lesions.

Therefore, in the context of delivering a service to this group of patients, three generic factors pertaining to health care systems are relevant namely; the need for health care, the demand for and the utilisation of health services (Van Wyk *et al.* 1994a).

By definition the *client's need* for health care is based on the client's own perception of need, based on their experiences or awareness, whilst the *providers expression of need* is based on their professional judgement after examining the client. The client and provider perception may not always be congruent. The demand for care arises once a consumer perceives the need and s/he actively seeks health care. The quality of care, access to services, the knowledge and attitudes of the consumer influence demand. Demand is not always met (unmet demand). Utilisation occurs as the result of a perceived need, where the client actively seeks care and the demand is met.

2.7.1. Needs versus Demand for Care

Results from the 1988/1989 National Oral Health Survey in South Africa showed that the highest proportion of unmet demand for oral health care was observed in the African respondents, followed by Coloured, Asians and Whites (Van Wyk *et al.* 1994b). Emergency services such as pain relief and extraction procedures were reported to be most problematic with regard to access; with the main reasons being cost of care and the dentist being too busy (Van Wyk et al. 1994b). Perceived need for oral care in relation to epidemiologically determined needs for oral health care in South Africans showed that there was a discrepancy between the subjective perceptions of the consumer compared with the professional assessment of oral health worker (Gilbert *et al.* 1994). Perceived needs and potential demands differed by population groups, with African and Coloureds reported the highest demand for emergency care (Gilbert *et al.* 1994). These variations were explained by the different "social realities" of the subgroups, highlighting the need to consider the clinical as well as the social factors when determining health care needs and planning services (Gilbert *et al.* 1994).

Limited studies on the dental health needs, demand for and utilisation of oral health services for South African HIV-infected persons have been reported in the literature (Camara 1996). A South African study examining the perceived health information needs of HIV-positive persons showed that information on oral health was ranked second, with information on disability grants being highest and information on recognising simple diseases as third (Camara 1996). A study examining unmet demands of 1851 HIV-infected persons

in the USA showed that services such as dental, mental care and medications were more likely to be unmet than the need for emergency or hospital care (Bonuck *et al.* 1996). A study of a USA cohort prioritising HIV-health care needs showed that the needs were highest for medical (85%), followed by dental (70%) and mental health (69%) respectively (Marx *et al.* 1997). Unmet needs in the same group were most common for dental (41%) and home care (40%) (Marx *et al.* 1997). Whilst it may be argued that factors affecting need, demand and utilisation of oral health services for HIV-infected persons is similar to the general population, it is important to examine this particular group as studies suggest that over and above the generic factors that affect need, access and utilisation, there are specific factors linked to the HIV-status of an individual that influence these factors. A study examining the attitudes of HIV-infected persons towards their own dental care in the United Kingdom showed that the majority of the participants (74%) changed dentists or stopped seeking dental care following their diagnosis with HIV (Gallagher, Gealer & Birnbaum 1998). The main reasons given for this behaviour were the fear of or actual refusal of treatment, or the desire to seek care from a more sympathetic health care provider (Gallagher, Gealer & Birnbaum 1998). The need to understand the relationship between the perceived need of the client and the normative need of the provider with regard to oral HIV-related morbidity is relevant as this impacts on utilisation and access to care.

2.7.2. Utilisation of and Access to Services.

Utilisation and access to oral health services are influenced by a number of factors such as cost of care, distance from service, fear of dentists, language barriers, long waiting time and not knowing where to go. The National Oral Health survey of 1988/1989 revealed that the reported barriers to oral health care varied by population and income group, with twice as many of those classified indigent, reporting financial barriers compared with the non-indigent group (Faber *et al.* 1994). A significantly higher proportion of non-indigent group reported attitudinal barriers as the reason for not visiting a dentist regularly (Faber *et al.* 1994).

A study examining utilisation of services by HIV-infected persons in the United Kingdom showed that 60% of patients had not visited a dentist after having known their HIV status, 32% were refused care whilst 10% had attended without disclosing their status (Robinson & Croucher 1993). Similar findings were reported by Gallagher, Gealer & Birnbaum (1998), in a study of HIV-infected individuals attending support groups in the United Kingdom.

In South Africa, research has focused largely on the health care provider perspective on the delivery of care to HIV-infected persons and to a lesser extent on the patient perspective (Darling, Arendorf &

Samaranayake 1992; Hartshorne *et al.* 1994; Camara 1996; Rudolph & Ogunbodede 1999). Camara (1996), in a study of South African HIV-infected persons showed that 57% percent of patients preferred to visit private dental clinics rather than community clinics due to long waiting times at public facilities. Mascarenhas & Smith (1999), showed that utilisation of oral care by HIV-infected persons was extremely low, with socio-demographic variables being significant determinants of utilisation. Since there is limited literature on oral health utilisation of and access to oral health services for HIV-infected persons in South Africa, it is appropriate to explore this area. This information may be useful for health care providers in planning and providing appropriate services.

One could argue that socio-demographic factors such as education, income and ethnic origin are also significant determinants of care in the general population. However, what is important is that the HIV-infected group, is not homogenous, and that within this group special emphasis should be placed on those from low income levels, with poor education and poor access to care (Mascarenhas & Smith (1999).

Access to oral health services is influenced by oral health workers' (OHW) attitudes and willingness to treat HIV-infected persons as well as the resources available for the delivery of care. A study in the Western Cape Province showed that only 16% of dental students felt comfortable treating HIV-infected persons (Shaikh, Hamekar & Moola 1998). A study examining the knowledge and attitudes of oral health care workers in the public sector in South Africa revealed that the majority of respondents expressed the need for additional education on the management of HIV-infected persons and only 61% believed that they were legally obliged to treat HIV-infected persons (Rudolph & Ogunbodede 1999). The South African Dental Council states that there is a moral, ethical and legal obligation to treat HIV-infected persons (South African Medical and Dental Council 1994). The above highlights that there is a need to develop the capability of clinicians to deliver appropriate oral health services as well as acting in agreement with the SAMDC code of ethics.

However, the grim reality is that a large proportion of oral health care workers in the public sector reported that the facilities in their clinical environment were inadequate to ensure universal precautions (36%), with many reporting that they did not have access to written post-exposure protocols (45%), or medications (55%) for needle-stick injuries (Rudolph & Ogunbodede 1999). These deficiencies in the work environment may be a cause of additional anxiety amongst clinicians, which in turn affects the quality of care. The arguments around scarce resources have become particularly relevant since the implementation of decentralisation

strategies where there has been a shift from specialised care to comprehensive services at primary level (Shaikh *et al.* 1997).

2.7.3. Are Dedicated Services the Alternative?

The debate on various models of service delivery (dedicated versus comprehensive services) for HIV-infected persons remains unresolved both internationally and locally (Croucher *et al.* 1997). Current thinking in South Africa is geared toward the development of comprehensive services in the context of the National Health Plan. Most studies in South Africa that have examined the delivery of primary health care for HIV-infected persons have focussed on medical services (Karstaedt et al. 1996). A limited number of studies have examined the provision of primary care for oral HIV-related disease in South Africa. A survey of oral health care workers from the public sector revealed that only 30% of the participants felt that patients should be treated in the public sector (Rudolph & Ogunbodede 1999).

One of the greatest challenges health care planners currently face in South Africa, is the transformation of the public health services by shifting resources from specialised, tertiary levels to primary levels where comprehensive care is rendered. It is widely acknowledged that shifting care from specialised tertiary to comprehensive primary care settings for HIV-related conditions has its limitations. These include a combination of factors such as skills shortages, scarce resources at primary levels of care and patients' unwillingness to be treated in the community that they reside in because of the fear of losing anonymity (Shaikh *et al.* 1997). The rising prevalence of HIV infection in South Africa and the anticipated increase in the demand for oral health care, may not permit dedicated clinics to be a viable alternative to comprehensive services for economic and logistical reasons. Hence, from an oral health perspective it would be important to understand the opinions of planners and providers of care with respect to the delivery of oral health care to HIV-infected persons. It would also be appropriate to explore their views on methods of overcoming the limitations they experience.

2.7.4. The Cost Implications on Service Delivery

With the growing epidemic in South Africa, care for HIV-infected persons is placing a huge financial burden on public sector services. It is estimated that by the end of the year 2000, the associated health care costs would be 19-49% of the total health care expenditure, equivalent to 5.1% of the Gross National Product (GNP) (Doyle *et al.* 1991). Evidence shows that HIV-related illnesses consume a third of the health care

budget in developing countries with high rates of infection (Foster 1994). Therefore, in order to plan and provide affordable and appropriate care, information on the profile of patients seeking care, care strategies and cost estimates are imperative (Kinghorn *et al.* 1996). The major constraint that hinders the estimation of health care costs in South Africa is scarcity and poor quality of data on the clinical presentations of HIV disease in the general population. The existing health information systems in the public sector services are deficient with regard to accessing accurate data on facilities, equipment and consumables (Barrie, Personal Communication 30 September 1999). This has been further complicated by the process of restructuring the health services, whereby it is difficult to monitor changes in the period of transition.

Similarly, the estimation of the cost of providing dental care for HIV-infected persons in the public sector services in South Africa is hindered by the lack of information on service utilisation by this group. Most studies that have examined the cost of treating oral HIV-lesions in SA, have done it as a component of medical care costing, as certain oral lesions are treated by medical personnel (Karstaedt *et al.* 1996; Kinghorn *et al.* 1996). It is important to note that these costs may be an underestimation of true costs as studies have shown that medical clinicians tend to under-diagnose oral HIV-lesions (Cruz *et al.* 1996). The gap in the oral health literature on estimating the cost of treating oral HIV-related lesions is evident both locally and abroad. Most of the literature on oral HIV service delivery focuses mainly on the implications of infection transmission in the dental setting, protection of the clinician and the patient experience. Estimating the cost implication is critical for the delivery of oral health care and the allocation of resources.

2.8. Summary

This review highlighted the importance of oral lesions in the natural history, diagnosis and treatment of HIV infection. It also showed that the prevalence of oral lesions related to HIV infection is highly variable. This stems from a range of methodological approaches adopted in various studies. The occurrence of these lesions is multifactorial, influenced by a combination of factors such as host, environmental, systemic and demographic. It has emphasised the importance of correct diagnosis of lesions, the early detection and the appropriate management of HIV-related illness. Oral health management for HIV-infected persons must be broadened to include a wider scope of care which should include factors such as improving the capability of clinicians to treat patients appropriately, engaging with other health care providers with respect to the

general health status of the individual and improving access to care. The direct cost implications were also briefly explored from a service delivery perspective. This information can be useful for policy makers and planners, highlighting the potential financial implications of the epidemic on the oral health care budget. It is in this context that the following aims were proposed

2.9. AIMS

1. To examine the oral clinical presentations of HIV infection in relation to the contributory factors.
2. To understand the patient and provider perspective with respect to the delivery of oral health services to HIV-infected persons.
3. To estimate the cost of treating HIV-related lesions.

2.10. OBJECTIVES

For Aim One

1. To measure the prevalence, sites and number of oral lesions related to HIV infection in a group of hospital attenders.
2. To identify the determinants of oral HIV-related lesions through regression analysis.

For Aim Two

3. To examine factors that influenced utilisation and access to oral health services by HIV-infected persons.
4. To explore the health provider perspective with regard to the delivery of oral HIV care.

For Aim Three

5. To estimate the cost of treating HIV-related oral lesions.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1. INTRODUCTION

This study comprises of three components in order to meet the objectives. The first part was a cross-sectional survey examining prevalence and determinants of oral HIV-disease. It included a structured interview section that also examined the utilisation of and access to health services by HIV-infected persons. The second component consisted of a qualitative survey, which focused on the opinions of key informants on the delivery of oral health care for HIV-infected persons in the public sector. The third component was a costing exercise, which was carried out to estimate the direct costs of treating these lesions. The methodology of the cross-sectional study, the qualitative study and costing exercise are presented separately in this chapter.

3.2. CROSS SECTIONAL STUDY

Objective One and Two: Prevalence and Determinants of Oral HIV-lesions

Objective Three: Access and utilisation of HIV Oral health services

3.2.1. Study Design, Site and Sampling

This study formed the oral health component of a collaborative study of the natural history of HIV disease. It was done in collaboration with the HIV Cohort study team, based at the University of Cape Town Medical School. The team consisted of medical specialists, social workers, nutritionists and a dentist. Participants comprising of adult HIV-infected heterosexual and homosexual persons were examined at the medical outpatient department of Groote Schuur Hospital. A sample of 239 individuals were consecutively recruited from the clinic appointment list. The patients were referred from private practitioners, hospitals, clinics or the outpatients department of the hospital.

3.2.2. The Inclusion Criteria

The criterion for inclusion into this study was the presence of an infection with the Human Immunodeficiency Virus. This was determined by testing for HIV antibodies using the Elisa and Western Blot techniques. Patients who were attending for a follow-up visit from a previous appointment were excluded in order to avoid double counting. The hospital number was used as a unique patient identity number in order to avoid double counting and keeping track of patients. Hence, the 239 adult subjects represented patients who were examined for the first time in the cohort.

3.2.3. Main Observation / Outcome

The outcome variable was the presence of oral HIV-related lesions. The lesions were diagnosed using a modified EC-Clearinghouse and WHO Collaborating Centre criteria for oral HIV-related lesions (EC-Clearinghouse 1993). A modification was made to the recording of leukoplakia on the lateral border of the tongue. The examiner noted whether they were non-corrugated or corrugated (hairy leukoplakia). Begg *et al.* (1996) reported these differences and cautioned the reader with regard to misdiagnosis and its implications on staging of HIV-infected persons. For this study, the presumptive criteria according to the EC Clearinghouse guidelines were applied in conjunction with the response to antifungal therapy and/ results of candidal smears to eliminate the possibility of a candidal lesion (EC-Clearinghouse 1993).

Unlike the EC-Clearinghouse Classification, Median Rhomboid Glossitis (MRG) was noted in this survey for clinical description purposes only. Previously this lesion was thought to be a developmental defect resulting from a failure of the tuberculum-impar to retract before fusion of the lateral processes of the tongue (Firriolo 2000). More recently, it has been proposed that it is a chronic form of candidiasis (Firriolo 2000). Touyz and Peters (1987), in a retrospective study of MRG lesions described matching oral lesions on the palate, suggesting a relationship between the two lesions and reported that they were related and of Candidal origin. Although MRG is not included separately as a distinct clinical entity in the EC-Clearinghouse Classification System, these lesions have been observed as a different form of a chronic candidiasis in HIV-infected persons and recent recommendations have been made to include them in the classification system separately (EC -Clearinghouse 1993; Kolokotronis *et al.* 1994). Therefore in this study, lesions were considered to be of candidal origin and included as erythematous candidiasis. For clinical description purposes only, these lesions are noted separately to highlight the number of lesions that fall into this category.

In accordance with the EC-Clearinghouse guidelines, the diagnosis of oral candida was based on the presumptive criteria, except for select cases of erythematous candidiasis, where resistance to antifungal therapy was suspected, or when oral hairy leukoplakia had to be ruled out. These lesions were confirmed with a microscopic evaluation by taking a surface smear followed by a Periodic Acid-Schiff staining. As noted in the EC-Clearinghouse document, angular cheilitis can be associated with *Candida* and may be seen in HIV-infected persons. These lesions were therefore included in the clinical description (EC-Clearinghouse 1993).

For the periodontal lesions, linear gingival erythema, necrotising (ulcerative) gingivitis and necrotising (ulcerative) periodontitis were recorded on the basis of the presumptive criteria, as there are no definitive criteria recommended according to the EC-Clearinghouse group guidelines (EC-Clearinghouse 1993). Whilst it is recognised that periodontal disease and chronic marginal gingivitis may occur in HIV-infected persons, it was not possible to clearly diagnose the above lesions because of the unavailability of radiographic equipment at the study site. Anecdotal evidence from the patient pointing that it existed prior to the HIV infection as described by Arendorf *et al.* (1997) was considered. However, given the difficulty in ascertaining this type of information and the concern about introducing subject bias, this approach was not taken. The absence of clear protocols in diagnosing the above lesions at the time of the study was the prime reason for excluding these lesions in the diagnosis. More recently, firmer recommendations have been proposed by Robinson (1998) with regard to the inclusion of these lesions.

Xerostomia was noted where there was evidence of dry mucosa and/ or when the patient complained of dryness of mouth. It was not possible to measure salivary flow rate given the time constraints and limited resources at the study site. These manifestations were noted in the context of accessing clinical information for the appropriate management of the patient and were not included in the measurment of oral lesion prevaelnce. Melanotic hyperpigmentation were also recorded as this lesion is reported to present in HIV-infected persons although the pathological significance of this lesions is unknown (Schiφdt 1997).

3.2.4. Measurement

Objective One: Prevalence and Types of Oral HIV- Related Lesions

The prevalence of oral lesions was assessed by calculating the proportion of the sample that had oral lesions related to HIV infection. The number of sites and types of lesions were recorded.

Objective Two: Assess the Determinants of Oral HIV-related Lesions

Objective Three: Utilisation and Access to oral HIV care.

The demographic factors and other possible risk factors were examined in relation to outcome variable(oral lesion/s). This included factors such as occupation, gender, oral health status, drug intake, access to oral care, presence of TB[3], smoking and alcohol intake as possible contributory factors.

3.2.5. Data Instrument

The instrument used in this study was a modified three-part instrument, developed by a team of researchers at Columbia University, New York (Lamster *et al.*1994). The first part was the medical history and general medical health measures. This comprised of a demography section, general physical health status, stage of disease, immunologic status, (CD4 cell counts, CD8 cell count and blood counts) and the presence of medical conditions such as TB, *Pneumo Cystis Pneumonia* (PCP), cancers. (Appendix 1).

The second part consisted of a section for specific diagnostic information on the oral health status such as location of lesions, size of lesion, clinical diagnosis and colour of lesions. It also included the oral health measurements such as debris and calculus indices, decayed, missing and filled teeth (DMFT) scores and laboratory findings (Appendix 2). The Simplified Debris Index and Simplified Calculus Index as components of the Simplified Oral Hygiene Index was applied (Greene and Vermillion 1964). This was to quantitatively assess oral cleanliness by estimating tooth surface covered by debris or calculus. Each individual patient was assessed by examining six index teeth using the criteria by Greene and Vermillion (1964). The individual score was calculated by adding the scores of individual teeth and divided by the number of teeth examined. The scores were then grouped using a nominal scale to evaluate the scores[4].

The third part was a structured interview questionnaire, which recorded utilisation of and access to oral health services by the subjects (Appendix 3).

The questionnaires were piloted on 20 individuals and the questionnaires were revised for minor layout changes to improve ease of administering the forms. The piloted forms were included in the final sample.

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[3] The diagnostic criteria for TB was based on special criteria developed by the researchers/clinicians at the hospital site. This included a combination sputum smear and culture tests, serology, radiographs and clinical presentation.

[4] The DI and CI scores were grouped in the following manner 0 , 0 .1- 0.6, 0.7-1.8, 1.9-3.

3.2.6. Data Collection

The participants were recruited from the clinic queue, after which informed verbal and written consent was obtained (Appendix 1). A full medical examination and an oral examination were carried out thereafter. The medical evaluation was carried out by the medical specialists of the clinic. The examination included an interview and a physical examination. Symptoms and the history of diseases related to HIV infection were recorded in the forms. Patients were staged using the WHO HIV-staging system (WHO 1990). The immunological examination included the recording of CD4 % and raw score, CD 8 cell counts and total White Blood Cell counts. After medical examination forms were completed, the details were made available to the oral health researcher.

The oral examination was done by a dentist (the author) trained in HIV-related oral diseases. The site(s) and number(s) of lesions were recorded in a WHO developed pictogram for mapping oral lesions. Mucosal smears were taken using a cytobrush or tongue blade and smears were fixed with alcohol. Lesions were classified according to the EC-Clearinghouse definition (EC-Clearinghouse 1993). Photographs were taken routinely and used for calibration purposes. Variables such as smoking, alcohol consumption, recreational use of drugs, medication, and socio-demographic status were recorded in the oral health questionnaire. Structured interviews explored the utilisation and access to health services. Patients were given an opportunity to ask questions and given oral hygiene education. Medications were prescribed where necessary, and patients were referred for additional care if required.

3.2.7. Cofactors and Potential Confounders

The following factors were assessed: Drugs, ethnicity, gender, occupation, alcohol consumption, and smoking, use of recreational drugs, immune status (CD4). Drug intake (recreational and medication) together with other harmful substance intake were assessed through interviews. The results were verified with the information from the medical and social worker reports in the hospital files.

3.2.8. Sample Size & Power

On the basis of previous studies which showed that oral lesions present in 60-90% of HIV/AIDS patients (Arendorf *et al.* 1997; Maresky 1996), and given that approximately 800 new patients were seen at the HIV

outpatients clinics per annum (Maartens , Personal Communication 1996), significant results can be detected with a power of greater than 80% and at significant levels of 0.01, in a sample size of 239 participants (Fleiss 1981).

3.2.9. Calibration, Reliability and Validity

The researcher was calibrated by undergoing diagnostic training for oral diagnosis of infectious diseases according to the EC-Clearinghouse definitions (EC-Clearing House 1993). A review of the diagnosis was carried out with the use of photographs and forms with an Oral Medicine consultant. This was done in consultation with Dr Amenah Shaikh, who was a Principal Dentist and an Oral Medicine and Periodontology consultant at the University of Western Cape. The researcher was also trained by Dr Joan Phelan and Dr R Bucklan from the School of Dental and Oral Surgery, Columbia University, New York. For inter-examiner reliability, repeat examinations were carried out in the pilot phase on 20 subjects until over 90% agreement was reached using the *Kappa* test (Fleiss 1981) (Appendix 4). Intra-examiner reliability was also tested for the diagnosis of lesions (Appendix 4). Certain clinical diagnoses, such as candidiasis were confirmed by laboratory tests as earlier specified. Given the difficulty in addressing external validity, the findings were interpreted and compared with studies carried out locally and abroad (Scheutz 1997). This is presented in the discussion chapter of this document.

3.2.10. Data Management

The quantitative data was entered onto pre-coded forms. Keypunching was done twice for verification (SPSS Inc 1996). Data was cleaned and checked by the data capturers from the Medical Research Council. Blank answer boxes were regarded as missing and a no response option was provided in the questionnaire. To avoid the inappropriate leakage of sensitive information, the original forms were returned to the principal investigator for safekeeping and participants were identified by codes and not by name during the re-handling of data. In addition, the data was not placed on a network system. Data was analysed using the Statistical Package for Social Sciences (SPSS) and Statistical Analysis System (SAS) (SAS Ltd 1991; SPSS Inc 1996).

3.2.11. Literature Review

The literature search was done through a MEDLINE search of HIV/AIDS and the oral manifestations for the period 1981 to February 2000. Abstracts and other relevant material were searched on the Internet and hand-searched in libraries. Some of the key words used included oral manifestations, oral lesions, HIV lesions, oral lesions, health care, health services, dental care, dental care cost, quality of care, HIV infections. Abstracts referred to were from all languages, however full articles were only English medium one. The use of only English articles is recognised as a limitation of the review.

3.2.12. Statistical Analysis

Percentages, odds ratios, Chi square tests, stratification and logistic regression analysis were the tests employed for the analysis of the results.

Objective One: To measure the prevalence of oral HIV-lesions

Categorical variables were used to determine the prevalence, type, number and site(s) of oral HIV-related lesions.

Objective Two and Three: To assess determinants of HIV-related lesions.

For the categorical variables, the adjusted method of Mantel-Haenszel Chi Square Test was used. (Fleiss 1981). The Mantel-Haenszel Odds Ratio was computed to test for the strength of the association and Odds Ratio were noted (Fleiss 1981). To test the associations between continuous variables, the Student's *t* test was used. Stratified analysis was done prior to performing a multivariate analysis to determine the existence of individual confounding variables. Alcohol intake, use of recreational drugs, age, gender, smoking and other covariates were examined separately for confounding. A stepwise logistic regression model was used to test the relationship between the presence of oral lesions (outcome variable) and the presence of several cofactors (SPSS Inc 1996). Variables that were significant at alpha level of 0.05 were systematically examined by inserting them into the logistic regression model. In addition to the variables that showed significant relationships with the outcome, factors that have been shown previously in the literature to be significant correlates of Oral HIV-related lesions, or have a biologically plausible relationship with oral HIV-lesions, were inserted into the regression model. Furthermore, based on the recommendation by Rothman (1990), both measures (i.e., p values and confidence intervals) are used to assess the relationship.

Variables were included in the model even if p-values were greater than 0.05, but where large confidence intervals were obtained.

This was done given that large confidence intervals may be suggestive of a small sample size and significance may not be obtained even if there was a relationship. A stepwise regression model was the method of choice to suggest an initial model.

Th e model to predict the occurrence of oral HIV-lesions was based on the following equation:

$$Y = a + bX_1 + bX_2 + bX_n$$

X_1, access to care, X_2, Age, X_3, Ethnic status, X_4.etc .(Table 5).

Y is the outcome variable: presence of oral HIV lesion(s)

X_1, X_2, X_3, X_n are the risk or explanatory variables

b= coefficients or beta weights

a = the point at which the regression line intercepts the Y-axis

The initial model was refined to develop a final model that predicted the outcome (oral lesion/s), whilst adjusting for possible confounders. The estimates of Odd Ratios and significance levels were shown. An Alpha level of 0.05 was used as a criterion for significance.

3.3. QUALITATIVE STUDY

Objective Four: To explore the health care provider perspective on the delivery of oral HIV-related care.

A qualitative study was carried out by conducting, structured, in-depth interviews with key informants (n=15) using a purposeful sampling method. Participants included oral health clinicians (6), dental consultants (3), medical consultants (3), health policy makers and program managers (3). With permission from the interviewees, the interviews were recorded on the structured interview questionnaires (Appendix 5). A schedule was developed for the interview exploring opinions in the context of the delivery of oral health care for HIV-infected persons in the public sector. These included barriers to care such as the role of dedicated clinics, the link of dental care with other services, recommendations for the delivery of care and

the possible limitations in their work setting. The schedule was piloted prior to data collection. Content analysis was carried out to explore for common themes and these were coded for descriptive analysis.

3.4. COSTING STUDY

Objective Five: To estimate the cost of treating oral HIV-related lesions.

A cross-sectional analysis was carried out on HIV-infected patients at Groote Schuur Hospital. A sub-sample of 159 records were drawn from the larger Oral HIV Study sample of 239 patients. The purpose of this exercise was to estimate the cost of treating the oral lesions for the purposes of highlighting the cost implications on service delivery. The criteria for selection into this part of the study required that the individual had an oral HIV-related lesion at the time of the visit which required treatment. The details of the oral HIV lesion, type of treatment provided, medications prescribed, stage of disease, presence of TB as well as the CD4 counts were recorded. The treatment for each patient was itemised.

The estimated cost of care in Rands per visit, was calculated using the sum of drug cost, consultation fees, oral hygiene care, laboratory investigations and infection control cost. The drug costs were based on the prices of drugs bought on the public sector tender. A dispensing fee was added to the drug costs. Laboratory costs and procedure costs were based on the 1997-8 recommended schedule of fees prescribed by the Representative Association of Medical Schemes (RAMS). (Dental Association of South Africa & Representative Association of Medical Schemes 1998). The average cost of care in Rands for the sample was determined after adding individual costs namely, consulting fee, oral hygiene, drugs, infection control and laboratory investigations; and dividing it by number of patients treated (n=159) (Appendix 7). Laboratory investigations included cytological smears for *Candida*, biopsy for Kaposi's sarcoma, biopsy of ulcers for CMV investigation. The average cost by disease stage was measured and using a *t*- test to detect significant differences in the mean cost by HIV disease stage.

The projected cost was determined on the basis of the following assumptions:

- Oral HIV-related morbidity will present in 60%-70% of the sample. This was based on the pilot results of the current study and another South African study (Arendorf *et al.* 1998).
- The utilisation of dental services based on the findings of this study was that 30% of the participants will seek oral care if they had oral lesions at a given point in time.

The demographic data was based on the 1996 Census with projected estimates (Statistics South Africa 1998). The prevalence of HIV infection was based on the annual HIV national survey (Department of National Health 1999; Department of National Health 2000). The provincial oral health budget allocation was obtained from the Deputy Director: Oral Health, Western Cape (Department of Health 1998). On the basis of the above, the projected cost of care was estimated, taking into account the changing prevalence of HIV disease by year, the average cost of care in this study as well as the assumptions listed above. The projected cost assuming a 60% and 70% prevalence of oral HIV-lesions, was then compared with the provincial oral health budget. Trends of the projected cost was compared with oral health allocation for the period 1994 to 1997. The projected cost was also measured as a proportion of the provincial oral health budget allocation. Data was captured on a spread sheet and descriptive analysis were made using the SPSS software package (SPSS Inc 1996).

3.5. ETHICAL CONSIDERATIONS

The research proposal for study one was submitted for peer review to the Centres of Epidemiological Research South Africa (CERSA) of the Medical Research Council (MRC) and submitted to the MRC ethical committee for ethical review. It was approved and funded by the Medical Research Council in South Africa and University of Western Cape. Permission to work at the sites was obtained from the institution through the senior consultants of the respective sites. They were Prof. Gary Maartens and Dr. Robin Wood. The other components were approved by the Faculty of Dentistry, Oral Health Centre, University of Western Cape ethical committee. Informed consent was obtained from the participants in written and verbal form. The client was informed of the purpose of the study, the benefits and potential risks and their right to refuse participation (Appendix 1). The participants were compensated for their input by providing a free consultation and arranging for dental treatment where necessary. Oral hygiene education was also done routinely. On a weekly basis, the researcher provided an oral health screening service at the dedicated clinics where data was collected. All the data sheets except for study one were coded with unique identity numbers and not names. For study one, a tear sheet system was used, whereby after examination and interviews, the names and addresses of the participants was torn off and replaced with a number. Names and addresses were kept in a separate file which only the principal researcher had access to. These records were kept for the purposes of following up patients for future treatment and/ or follow up. The data was analysed in aggregate. The data was not placed on a network system.

CHAPTER FOUR: RESULTS

4.1. INTRODUCTION

This chapter begins with a description of the demographic features of the sample of HIV-infected persons. It is followed by a presentation of the clinical and immunologic status of the study participants. The clinical features of the oral HIV-related lesions are presented, highlighting the clinical manifestations in terms of the frequency, location and number of lesions. The significant determinants of oral lesions are presented, first, through the bivariate analysis, showing the relationship of a single potential contributory factor with the outcome variable, namely, oral lesion/s. This is followed by the results of the logistic regression analysis, showing the relationship of multiple contributory factors with the outcome variable, namely, oral HIV-related lesion/s. The patient perspective on oral health care is presented, with an emphasis on the utilisation of services, access and barriers to oral health care. This is followed by an examination of patient perceptions and their experiences of the oral health services, linking, their perceived oral health status to the clinical oral presentation. The health care provider perspective based on the qualitative analysis focuses on mechanisms of delivering oral health services to HIV-infected persons, exploring concerns and identifying recommendations with regard to the delivery of oral health care in the public sector. Finally, the results of the cost analysis is presented, highlighting, the estimated and projected costs of treating oral HIV-related lesions.

4.2. DEMOGRAPHIC FEATURES

The demographic features are presented in Table 2. The sample (n =239) comprised mainly of African (64%), heterosexual (89%), and were between the ages 20-39 years (75%). Fifty six percent of the sample were unemployed and 31% lived in informal settlements or shelters. Only 6% of the sample had third party medical cover.

Table 2. Demographic Features of the Sample

Variable	Percentage (n=239)
Gender: Female	52%
Age in years	
<20	3%
20-29	41%
30-39	34%
40-49	16%
50+	6%
Highest Level of Education	
Primary level	8%
Secondary level	91%
Tertiary level	1%
Employment Status: Employed	44%
Sexual Identity	
Heterosexual	89%
Homosexual	9%
Bisexual	2%
Ethnic Group*	
African	64%
Coloured	24%
Indian	1%
White	11%
Housing	
Informal Settlement	29%
Brick House	60%
Prison	8%
Shelter	2%
Other	1%
Third Party Medical Cover †	6%

* Prior to the democratic elections in 1994, all people in South Africa were classified according to the Population Act of 1950. The use of these terms does not imply their legitimacy.

† Includes Medical Aid, Health Maintenance Organisations and Medical Insurance

4.3. THE MEDICAL, CLINICAL AND IMMUNOLOGIC PROFILE

The clinical, medical and immunologic profile is shown in Table 3. Thirty six percent of the sample were cigarette smokers, 21% consumed alcohol daily and 16% smoked marijuana at the time of the study. Tuberculosis was present in 26% of the sample, whilst 21% were in WHO stage one (asymptomatic) at the time of the visit. Seventy-six percent of the subjects were currently taking western prescribed medication, with antibiotic intake being most prevalent (46%). Thirty-six percent were consuming traditional medications only and 25% were taking a combination of western prescribed medication and traditional medications.

Table 3. Medical, Clinical and Immunologic Profile.

Variables	Percentage / Mean (Standard Deviation)
Tuberculosis	26%
WHO Stage of Disease	
Stage One: Asymptomatic	21%
Stage Two: Symptomatic	20%
Stage Three: ARC	26%
Stage Four: AIDS	33%
CD4 Cell Count	300.6 (±288)
White Blood Cell Count	14.8 (±7.4)
Lymphocyte Count	1641(±1041)
Debris Index	
Scores *Rating*	
0 Excellent	18
0.1 - 0.6 Good	22
0.7 - 1.8 Fair	42
1.9 - 3.0 Poor	18
Calculus Index	
Scores *Rating*	
0 Excellent	26
0.1 - 0.6 Good	32
0.7- 1.8 . Fair	35
1.9 - 3.O Poor	7
DMF Score (all)	13.35(±9)
DMF (excl edentulous)	11.40(±8)
Edentulous	5%
Current Medication Intake	76%
Antibiotic	46%
Antifungal	22%
Antiviral	16%
Acyclovir	3%
Traditional medications only	36%
Combination of traditional and Western	25%
Cigarette Smoking Status	
Currently smoking	36%
Daily Alcohol intake *(at least once a day)*	21%
Marijuana Intake	16%

Note: Percentage is given for the categorical variables and mean ± standard deviation for the continuos variables

4.4. OBJECTIVE ONE: THE PREVALENCE AND TYPES OF ORAL LESIONS RELATED TO HIV INFECTION

4.4.1. Prevalence of Oral Lesions

Oral lesions related to HIV infection presented in 68.6% of the sample (Table 4) with 42.2% having two or more lesions at the time of examination (Table 5). Oral candidiasis (46.9%) was the most prevalent type of lesion, with the erythematous (28.9%) form being most common. Angular cheilitis was present in 17.6% of the sample and periodontal/gingival lesions in 20.5% of the sample.

Table 4. Prevalence of Oral HIV-Related Lesions

Lesion Type	N=239	Percentage
Oral Lesion/s	164*	68.6
Candidiasis	112	46.9
Pseudomembranous	39	16.3
Erythematous (Includes MRG n=17)	69	28.9
Angular Cheilitis	42	17.6
Hairy Leukoplakia	37	15.5
Corrugated	32	13.4
Non Corrugated	5	2.1
Periodontal /Gingival Lesions	49	20.5
Necrotising (Ulcerative) Periodontitis	16	6.7
Necrotising (Ulcerative) Gingivitis	7	2.9
Linear Gingival Erythema	26	10.9
Kaposi's Sarcoma	6	2.5
Recurrent Aphthous Stomatitis	11	4.6
Major Aphthous Ulcer	3	1.3
Minor Aphthous Ulcer	8	3.3
Pigmented Lesions	9	3.8
Papilloma	1	0.4
Herpes Simplex	7	2.9

* N=164 represents the number of individuals who have one or more oral lesions

4.4.2. The Prevalence of Multiple Oral HIV-lesions

Multiple lesions were examined in terms of same lesions in multiple sites and different types presenting concurrently (e.g. oral candida and hairy leukoplakia). Nine percent of the sample presented with multiple lesions of the same type at the time of examination. These included bilateral angular cheilitis, bilateral hairy leukoplakia and multiple Kaposi's sarcoma. Table 5 shows the proportion of the sample presenting with

multiple types of lesions occurring concurrently. Forty-two percent of the sample had multiple lesions with the most common combination being angular cheilitis with either linear marginal erythema or erythematous candidiasis. A significant relationship was observed between the occurrence of multiple types of lesions and mean CD4 cell count (p = 0.002).

Table 5. Proportion of persons with Multiple Types of Oral HIV-lesions

Number of Oral HIV-lesions	Percent	Mean CD4* Count
None	31.4%	407
One	26.4%	285
More than One Lesion	***42.2%***	
Two	21.8%	273
Three	14.2%	192
Four or more	6.2%	137

***p = 0.002**

4.4.3. Location of Lesions

The tongue (30%), angle of the mouth or lips (29%), attached gingiva (29%) and palate. (8%) were the sites most affected by the lesions. The unattached gingiva (2%) and floor of mouth (1%) were least affected by the lesions.

4.4.4.Clinical Presentation Photographs

Clinical photographs are shown in appendix 8

4.5. OBJECTIVE TWO: DETERMINANTS OF ORAL HIV-LESIONS

The results of the bivariate analysis, demonstrating the correlates of oral lesions are shown in Table 6. Significant associations were detected between the presence of one or more lesions and smoking, current medication intake, presence of tuberculosis, gender, alcohol and antibiotic intake. Poor access to care increased the odds of having an oral lesion by 4.6. Ethnic status showed a positive association with lesion presence although the association was not significant.

Table 6. Bivariate Analysis Showing Correlates of Oral HIV-lesions (One or more)

Covariate	Percentage	p value	Odds ratio
Gender: Male	78%	0.001	2.22
Age in years			
<20	-		
20-29	7%	0.002	-
30-39	63%		
40-49	75%		
50+	78%		
Sexual History			
Heterosexual	68%	0.44	-
Homosexual	81%		
Bisexual	67%		
Ethnic group:			
White	84%	0.06	-
Asian	0%		
Coloured	77%		
Black	63%		
Smoking			
Yes	93%		
No	69%	0.00	2.6
Alcohol			
Yes	88%		
No	64%	0.01	3.2
Medication Intake			
Yes	76%		
No	35%	0.00	1.7
Antibiotic Intake			
Yes	81%		
No	60%	0.02	2.6
Tuberculosis			
Yes	81%		
No	58%	0.00	2.4
Mean CD4 Cell Count	262	0.00	-
WHO Stage 1	55%		
WHO Stage 1	65%	0.00	-
WHO Stage 1	76%		
WHO Stage 1	82%		
Calculus Score			
Scores *Rating*			
0 Excellent	45%		
0.1 - 0.6 Good	67%	0.00	-
0.7 - 1.8 Fair	70%		
1.9 - 3.0 Poor	100%		
Access to Health care *			
Yes	67%	0.02	4.6
No	91%		
Oral Pain or discomfort	42%	0.17	-
Seek care when in pain	30%	0.15	-

*Determined using a 9-item question exploring the presence of poor access to care due to language, financial, fear of stigma, geographic, fear of rejection and not knowing where to seek care.

4.5.1. Regression Analysis of Oral HIV Lesion Presence

The logistic regression model was used to assess the association between determinants of lesions with the presence of one or more oral HIV-related oral lesion, while adjusting for potential confounding variables as listed in Table 6. Poor access to care[5] was the most significant correlate of disease. Local factors such as smoking and the presence of calculus deposits contributed to the occurrence of the oral lesions (Table 7). The ethnic status, gender and sexual identity were not retained in the final model, highlighting that they were not found to be significant when adjusted for the variable inserted into the model. The final model indicates that those individuals who had poor access to care were 6.36 more likely to have oral HIV-lesions than those with better access to oral health care.

Table 7. Logistic Regression Analysis of Oral HIV Lesion Occurrence in HIV- Infected Persons

Covariates	P value	Odds Ratio
CD4 count <200	0.008	2.07
Current Smoking	0.012	2.77
Calculus present	0.001	4.27
Poor access to dental care	0.012	6.36

4.6. OBJECTIVE THREE: UTILIZATION AND ACCESS TO ORAL HEALTH SERVICES BY HIV- INFECTED PERSONS

4.6.1. Utilisation of Services

The participants sought care mainly from the public health services (57%). The reported frequency of dental service utilisation was on average less than once per annum, with 72% seeking care for emergency treatment (Table 8). Ten percent reported that they had never been to a dentist in their lifetime.

[5] Poor access to care was defined by the reported barriers to care such as language, financial, fear of stigma, geographic, fear of rejection and not knowing where to seek care.

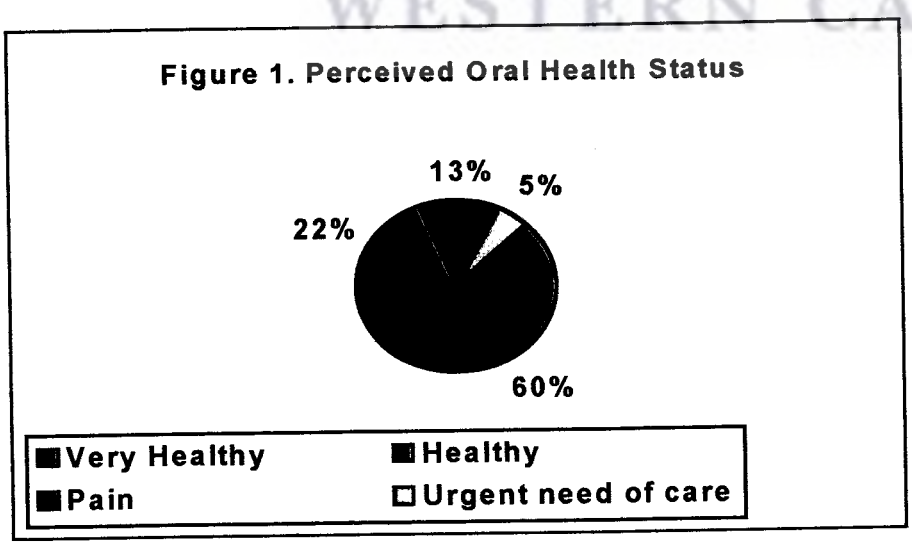
Table 8. Utilisation Patterns of Dental Services (n=239)

Variable	Percentage
Sites Where Dental Care was Sought	
Private Sector	23
Public Dental Clinic	57
Academic Hospital/Dental School	10
Never been to a dentist	10
Frequency of Dental Visits	
Once a year	5
2/3 times a year	8
once in 2-3 years	5
Emergency only	72
Never been to a dentist	10
Reason for Attending Last Dental Visit	
Pain	70
Check up	10
Ongoing care	7
Never been to a dentist	10
Other	3

4.6.2. Patient Perception of Oral Health Status

Figure 1 shows perceptions of patients of their oral health status. The majority of the sample considered their oral health status to be very healthy (60%) or healthy (22%). Thirteen percent reported that they were experiencing pain or discomfort whilst five percent perceived an urgent need for oral care.

Figure 1. Perceived Oral Health Status



4.6.3. Patient Perceived Need for Oral Care versus the Presence of Oral Lesions

A significant relationship was detected between perceived health status and the presence of oral lesions (Table 9). Sixty percent of those who perceived their oral health status to be very healthy had oral lesions. All those who thought they urgently needed care had oral lesions. The results shows that those who had been experiencing pain or perceived an urgent need for oral care, were more likely to have oral lesion/s.

Table 9. Perceptions of patients versus Presence of Oral Lesions (n=239)

Patient Perception of Oral Health	Presence of Oral lesions
Very Healthy	60%
Healthy	64%
Pain	70%
Urgently Need care	100%

p= 0.01

4.6.4. Barriers to Oral Health Care

Ninety-one percent reported poor access to care, with the major barrier being cost (33%). Note, only 4% had third party medical cover and 57% of the sample sought care in public sector clinics (Table 8 &10. Other barriers included fear of pain (21%) and fear of rejection (15%) due to HIV status. Of concern is the proportion of individuals (8%) reporting that they did not know where to seek oral health care.

Table 10. Reported Barriers to Oral Health Care: Patient Perspective

Variables	Percentage (n=239)
One/more barriers	91%
Cost	33%
Fear of Pain	21%
Fear of Rejection	15%
Fear of Infection	8%
Long waiting time	8%
Language barriers	8%
Don't know where to seek care	8%
Geographic inaccessibility	8%
Other	3%

Table 11. Access to Oral Care, Third Party Payment Cover & Gender by Key Variables in percentage

	Access Oral Care		Third Party Paymentφ		Gender	
	No	Yes	No	Yes	Women	Male
Age in years						
<20	2	-	2	12	3	2
20-29	41	43	43	22	47	34
30-39	33	43	33	56	31	37
40-49	17	10	16	0	14	19
50+	7	4	6	10	5	8
Calculus Score						
Scores *Rating*						
0. Excellent	27	28	25	54	29	25
0.1 - 0.6 Good	31	39	32	38	31	34
0.7- 1.8. Fair	34	28	35	8	35	31
1.9 – 3 Poor	8	5	8	0	5	10
Mean DMF Score (edentulous/dentate)	12/13	11/13	12/12	8/9	12/13	11/12
Brush Teeth						
Never	12	5	11	12	11	12
Month	3	5	3	0	3	2
Weekly	2	0	3	0	2	2
Daily	53	53	55	44	52	55
More than once daily	30	37	28	44	32	29
Third Party Cover Yes	3	10	NA	NA	3	4
Reported Dental pain and did not seek care	49	45	48	22	49	47
Ethnic						
White	*9	*28	11	12	*4	*18
Indian	1	0	1	0	0	1
Coloured	23	34	24	28	14	34
African	67	38	64	50	82	47
		-				
Unemployed	*69	*43	64	44	*75	*57
Gender						
Female	53	33	53	56	NA	NA
Male	47	67	47	44		
Oral Lesion/s						
Yes	*88	*11	88	68	*61	*78
Reason for previous dental visit						
Never been to dentist	18	0	78	6	13	8
Pain	77	78	4	11	67	69
Clean up	6	5	16	22	7	12
Routine	2	17	2	0	3	3
Smoke						
Yes	34	52	37	11	*20	*52
TB						
Yes	20	25	22	20	*14	*27
Dental Access						
Yes	NA	NA	8	22	*6	*12

Note: * P values ≤ 0.05. φ Third party payment: Dental Insurance, Medical Aid and Health Maintenance Organisation.

4.6.5. Access to Oral Care, Medical Insurance, Gender.

4.6.5.1. Access to Care versus No Access to Care

A smaller proportion of individuals had third party payment cover in the group without access to care (3%) in contrast to those with access to care (10%) (Table 11). Ethnic status was significantly associated with access to care, with a disproportionate number of Africans represented in the group with no access to care (67%) compared to those with access to care (38%). A significantly larger proportion of unemployed persons (69%) were represented in the group without access to oral care in contrast to the access group (43%). Oral lesions were significantly associated with access to care, with 88% of those without access to oral care having lesions compared to 11% with access. More individuals from the no access to care (12%) reported never to brush their teeth compared to those with access to care (5%).

4.6.5.2. Third party Cover versus No Third Party Cover

The mean DMF scores were significantly higher amongst those without third party cover compared to those with cover. A larger proportion of those without third party cover (48%) reported that they did not seek care despite experiencing oral pain compared to the covered group (22%). Amongst those without cover only 8% reported they had access to care compared to those with third party cover (22%).

4.6.5.3. Gender Differences

Fewer women (5%) than men (10%) had calculus scores in the 1.9 to 3 range. The DMF score was marginally lower in women. Significantly higher rates of unemployment were observed in women (75%) than in men (57%). Oral lesions were more prevalent in men (78%) than in women (61%). The prevalence of smoking and tuberculosis was also higher in men. Six percent of women had access to oral care compared to 12 % in men and fewer women smoked (20%) compared to men (52%).

4.7. OBJECTIVE FOUR: PROVIDER PERSPECTIVE

The qualitative analysis, which explored the health care worker perceptions on HIV-related to oral health care, was conducted through interviews. Fifteen staff, consisting of consultants from the HIV clinics, health managers and clinical staff from the clinics were interviewed.

Most of the participants (87%) felt that HIV-related care should be provided at all levels of care; namely, primary, secondary and tertiary care. The believed that the comprehensive approach would reduce the stigma attached to attending dedicated HIV-clinics (80%), enable easier access to care (53%) and is in line with the policy to shift primary care to the community settings (20%). However, 83% qualified by stating that *certain* categories of patients should be referred to the specialised settings. These included patients requiring surgical removal of teeth, treatment of persistent candidiasis and cancers related to HIV. They reported that the current situation in the public sector clinics did not permit them to carry out appropriate measures for universal precautions (73%). This, they feared endangered the patients' and their own safety.

Forty percent of the oral health care workers reported having experienced needle-stick injuries in the clinical settings. They expressed their dissatisfaction with the lack of proper guidelines for reporting and handling needle stick injuries, at the time of the interviews.

One clinician said, " *Although, I know that I need to report a needle-stick injury, I've had so many already that I have not kept track of them. In addition, drugs like AZT for prophylaxis are not readily available. There is no point really to then report the injury as it only leads to an increase in stress and anxiety."*

Those in favour of dedicated clinics (20%) said that patients may fear losing anonymity because they are likely to know the clinical staff of the Primary Health Care clinics in their community. They favoured dedicated clinics because of their perceived skills deficiency with regard to the management of HIV infections. Concern was raised that patients with unusual infections will not be diagnosed and treated early, resulting in complications which require costly specialised care.

The consultants from the medical dedicated clinics recognised the importance of decentralising the services to the primary care level although they felt that it was important to see the full spectrum of patients for research purposes. They viewed the interdisciplinary collaboration between oral health and medical staff in

the dedicated clinics as an important interaction that facilitates the delivery of high quality care. They recommended that a better referral mechanism and health information system between the dedicated clinics and community clinics needed to be established. They reported that often vital information and patients were lost due to the ineffective referral system.

Regarding the ability of existing systems to deliver HIV-care at the community clinics, there was a dissonance between managers and clinicians. Managers felt that staff were not making a concerted effort to screen and treat patients who were suspected of being HIV-infected. They attributed this to the lack of skills, fear of treating HIV-infected persons, overburdened services, or a general lack of interest on the part of the clinicians. Staff from the clinics reported that whilst recognising the need to be vigilant of high-risk persons they were often compromised by the lack of time and resources.

With regard to allocating resources, it was expressed that this be a priority especially in clinics where basic equipment was inadequate.

A clinician reported *"....We are provided with protocols and guidelines for the treatment of the patients. We don't have sufficient instruments, or the time to sterilise the instruments as prescribed by the manufacturer. We do not have strong gloves or adequate masks to protect ourselves or the patients."*

The staff felt that policy makers and planners were not sensitive to the difficulties they faced working in an environment of scarce resources and a growing number of HIV-infected persons. They felt the allocation of resources was inadequate. They recommended that management be made aware of the impact of HIV on the oral health sector.

4. 8. OBJECTIVE FIVE: COST IMPLICATIONS OF ORAL HIV CARE

The estimated cost of treating HIV-related oral lesions in the study is shown in Table 12. The data shows that consultation and oral hygiene education procedure consisted of 62% of the total cost, and drugs comprised 23% of the total. The average cost of per individual treatment was R130.73 per visit. There were no significant differences in the average cost detected in the group by WHO disease stage (Table 13).

Table 12. Cost of Treating the Oral HIV-lesions by Catergory in Rands (n=159)

	Examination	Oral Hygiene	Drug Cost	Infection Control	Laboratory Investigation	Total Cost
Sum of Individual Cost In Rands	6598.50	6248.70	4911.94	1621.80	1405.60	20786.54
Percent of Total	32%	30%	23%	8%	7%	100%

Average Cost R130.73

Notes: Procedure and RAMS codes (Appendix 7)

Examination 8104

Oral Hygiene Instruction 8151

Infection control 8109

Drugs varied according to item/s

Laboratory Investigations e.g. candidal smears, biopsy of ulcer, histology for CMV, Candidal culture.

Table 13. Average Cost of Oral HIV-lesions by Disease Stage

Stage	Average Cost in Rands
One	127.73
Two	122.74
Three	137.84
Four	131.34

P=(0.799)

4.8.1. Extrapolated and Projected Cost of Care

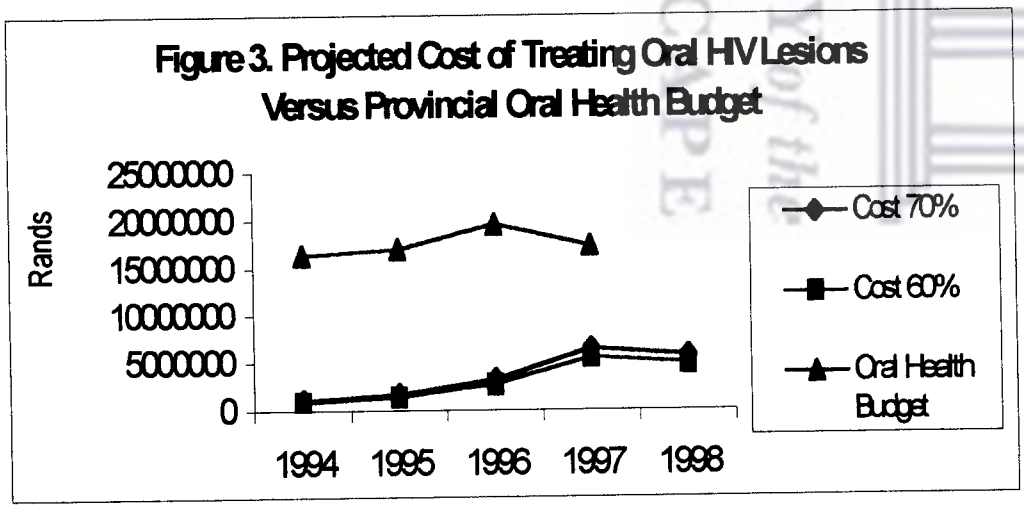
The estimated prevalence of HIV infection in the Western Cape Province was 3.1 % in 1996 (Department of National Health 1999). On the basis of the above, the assumption is that for a given population of 3936600 people in the Western Cape in 1996, 122035 individuals were HIV-infected.

Table 14 Trends: Estimated Cost in Rands for Oral Care

Year	%HIV	Population West Cape	Number of HIV persons	Number with Oral HIV-lesions		If 30% of those with oral lesion/s (60 %/70%) seek care		Cost of oral care @ R130.73 per visit		Allocated Oral Health Budget	Proportion of the Budget	
Ψ	β	Poplnϕ	HIV	60%	70%	60%	70%	60%	70%		60%	70%
1994	1.2	3 791 500	45 498	27 298.80	31 848.60	8 189.64	9 554.70	1 070 631.64	1249 085.93	16 522 000	6.5	7.6
1995	1.7	3 863 400	65 678	39 406.80	45 974.60	11 822.04	13 792.50	1 545 495.29	1 803 093.53	17 135 000	9.0	10.5
1996	3.1	3 936 600	122 035	73 220.76	85 424.22	21 966.23	25 627.20	2 871 644.99	3 350 243.86	19 676 000	14.6	17.0
1997	6.0	4 011 000	240 660	144 396.00	168 462.00	43 318.80	50 538.60	5 663 066.72	6 606 911.18	17 411 000	32.5	37.9
1998	5.2	4 086 900	212 519	127 511.28	148 763.16	38 253.38	44 628.95	5 000 864.89	5 834 336.10	Not Available	NA	NA

Sources: ϕ Census 1996, Statistics South Africa, 1998 β National Antenatal Survey, Department of National Health 1999

Ψ Sub- Directorate: Oral Health: Programme Development, PAWC 1998



According to oral health studies in South Africa and abroad, approximately 60-70% of people who are HIV-infected have oral lesions (Arendorf *et al.* 1998; Lamster *et al.* 1994). Hence, assuming 60% of the HIV-infected population will present with oral lesions; it is estimated that 73221 persons will experience oral lesions related to HIV-infection. However, not all persons with oral lesions will present for oral health care. This study showed that 42% of individuals with oral lesions were in pain or discomfort and 30% sought care when experiencing painful oral HIV-lesions (Table 6). On the basis of the assumption that 30% of those with oral HIV- lesions will seek care, the estimated cost of treating oral lesions in the public sector in 1996 was R2 871 644.99. Based on the above estimations, oral HIV-related conditions may have consumed 14.6% of the Provincial oral health budget. This increased by 32.5% in 1997.

4.9. Summary

This chapter highlighted that oral lesions related to HIV-infected persons presented in 68.6% of the sample. The number of lesions increased with disease stage. Oral candidal lesions were the most common type of oral lesions. The significant determinants of oral HIV-lesions were poor access to oral care, smoking, low CD4 cell counts and the presence of calculus. The major barriers to seeking oral care were cost, pain and fear of rejection. The oral health care providers expressed a range of concerns with regard to the delivery of care to HIV-infected persons. This included their own fears of being infected, inadequate resources and poor training. The cost of treating the oral lesions indicated that it would cost an average of R130.73 per visit, to treat the oral lesions. A large proportion of the cost consisted of consultation and oral hygiene fees (62%).

CHAPTER FIVE: DISCUSSION

5.1. OVERVIEW

This chapter centres around five aspects of oral health care for HIV-infected persons. Firstly, the prevalence of oral HIV-lesions is reviewed in relation to previously reported studies, focussing on the early detection and appropriate management. Secondly, the determinants of oral lesions related to HIV infection are discussed in relation to previous findings. Thirdly, the utilisation and access to HIV-related oral health-care is examined in relation to the broader determinants of health care provision in the context of developing guidelines to improve access. Fourthly, the provider perspective is explored in the context of the delivery of HIV-related oral care. Finally, the cost implications are examined at a macro-level, through the allocation of resources for oral health care.

5.2. OBJECTIVE ONE: PREVALENCE OF ORAL HIV-RELATED LESIONS

A large body of evidence indicates that oral lesions related to HIV-infected persons presents in more than two thirds of HIV-infected persons at some stage of the HIV-disease (Table 1 & 15). The findings in this study concur with previous studies in that 68.6% of the sample presented with oral lesions related to HIV infection (Table 1 &15). The most common type of oral lesions were oral candidiasis, which is similar to the observations in other HIV-infected South African cohorts (Maresky 1996 Arendorf *et al.* 1998). Since the beginning of the HIV epidemic several studies examining the prevalence of oral lesions related to HIV infection in various cohorts have been published (Table 1). These studies were largely descriptive. Over the last few years, there has been a shift in focus from describing the prevalence of oral HIV-lesions to assessing possible contributory factors in relation to the clinical findings (Table 15 & 16). These studies examined the relationship of oral lesions with the clinical, immunologic and demographic factors, where the analysis is adjusted for possible confounding factors (Palmer *et al.* 1996; Shiboski *et al.* 1996; Patton McKaig & Eron 1998; Ramirez-Amador *et al.* 1998; Matee, Scheutz & Moshy 2000).This is the approach taken in this study, where oral lesions were examined in relation to contributory factors. Table 15 presents a review of these studies highlighting the most common type of oral lesions.

Table 15: Review of Studies Examining the Prevalence of

Author Site	Cohort	Oral Lesions %	Most Prevalent Oral Lesions	Oral Candidiasis	HL	Ulcer	KS	PD
Lamster et al. 1994 ***USA***	IVDU Homosexuals N=160	69.6 64.2	***IVDU*** OC 43 ***Homosexuals*** White lesions 28	***IVDU*** OC 43 ***Homosexuals*** OC 17.3	29.1 28.4	7.6 13.6	0 4.9	39.1 21.3
Patton, McKaig & Eron 1998 ***USA***	Heterosexual Homosexual N=238	48	HL 26.5	OC 20 EC 4.2 PC 14.7 AC 2.9	2.6	4.2	1.6	8.8
Shiboski et al 1996 ***USA***	Men & Women N=218	22	M HL 22 W OC 24	OC 13 EC 3 PC 11 AC 2	M 22 F 9	M 2 F 5	NA	NA
Palmer et al. 1996 ***UK***	HIV Positive Dental patients N=456	AIDS 80 HIV 50	HL 30	OC NA- EC 24 PC 11 AC 6	30	13.6	3.7	7.7
Robinson et al. 1997 ***UK***	HIV positive Homosexual men N=312	59.6	HL 44.2	OC NA EC 6.9 PC 11.5 AC NA	44.2	6.4	4.5	NA
Tsang & Samaranayake 1999 ***Hong Kong***	Ethnic Chinese N=32	75	Minor ulcers 27.4	OC NA EC 6.9 PC 5.5 AC NA	11	39.7	0	4.1
Ramirez-Amador et al. 1998 ***Mexico***	HIV Positive Men & Women N=436	75	OC 38	OC 38 EC 26 PC 17 AC 10	M 31 F 28	M 8 F 0	M 3 F 0	M 2 F 0
Hodgson 1997 ***Zambia***	Adults N= 107	HIV 40 AIDS 55	HIV OC 25.2 AIDS OC 33.4	HIV/ AIDS OC 25.2/ 33.4 EC 6.5/ 11.8 PC 18.7/ 21.6 AC None	HIV 4.7 AIDS 5.8	HIV 4 AIDS none	HIV 8.4 AIDS 11.8	HIV 2.8 AIDS 3.9
Jonsson et al. 1998 ***Zimbabwe***	HIV positive Adults N=100	92	KS 72	OC 22 EC 5 PC 2 AC 5	none	26	72	3
Arendorf et al. 1998 ***South Africa***	HIV Positive Men & Women N= 600	60.4	OC 37.8	OC 37.8 EC 15.7 PC 15.5 AC 6.7	19.7	2.9	1.5	8.5
Current Study ***South Africa***	HIV positive Heterosexual Homosexual N=239	68.6	OC 46.8	OC 46.8 EC 28.9 PC 16.3 AC 17.6	15.5	4.6	2.5	20.5

Key HL: Hairy Leukoplakia EC: Erythematous Candidiasis PM: Pseudomembranous Candidiasis KS: Kaposi's Sarcoma NA Not Available
AC: Angular Cheilitis IVDU: Intravenous Drug Users M/W: Men/Women PD: Periodontal & gingival lesions OC Oral Candidiasis

5.2.1. Oral Candidiasis

Oral candidiasis were the most prevalent HIV-related oral lesions in this study (46.9%). This is similar to the observations made by Schiódt *et al.* (1990) in an African sample (43%), Robinson *et al.* 1997 (44%) in a heterosexual cohort, Arendorf *et al.* (1998), in a South African Cohort (37.8%), and Lamster *et al.* (1994) in a sample of Intravenous Drug Users (43%). Variation in the prevalence of these lesions may be due to a range of factors such as the composition of the sample (cohort, stages of disease), socio-demographic factors, diagnostic criteria, sample size and sample selection.

Erythematous candidiasis (28.9%) were more prevalent than the pseudomembranous form (16.3%). This compares favourably with previous studies by Palmer *et al.* (1996), Ramirez-Amador *et al.* (1998) and Arendorf *et al.* (1998) (Table 15). In contrast to the above, other studies reported a higher prevalence for the pseudomembranous form (Shiboski *et al.* 1996; Patton, McKaig & Eron 1998). Dodd *et al.* (1991), suggested that the subtle, asymptomatic form of erythematous candidiasis often goes undetected compared to the more obvious pseudomembranous type. Dental and non-dental clinicians are more familiar with the diagnosis of the classic pseudomembranous candidal lesions and are less vigilant of the other forms of candidiasis such as angular cheilitis and the erythematous form. The erythematous lesions have been reported to present as an early sign of HIV infection, and observed to be more prevalent in asymptomatic patients as opposed to AIDS patients (Pindborg & Nielson 1989). The authors suggest that the erythematous lesions precede the pseudomembranous lesions. This is supported by the findings of Robinson *et al.*(1997), in a British cohort, where pseudomembranous candidiasis were more strongly associated with the advanced stage of disease than the erythematous form. The study by Robinson *et al.* (1997) was cross-sectional, and therefore, the prognostic significance would have to be tested further through longitudinal studies. The failure to detect the more subtle erythematous lesions may have negative implications for the management of HIV disease. This supports the need to educate health care providers in appropriate diagnosis of oral HIV-lesions.

Angular cheilitis presented in 17.6% of the sample. This was much higher than that observed by Arendorf *et al.* (1998) in a South African Cohort (6.7%), but similar to the findings of Anil & Challacombe (1997), in a group of Indian patients with AIDS (24%). Differences in sample composition as alluded to earlier may explain the variation in prevalence. Angular cheilitis is often seen in patients suffering from malnutrition or

a debilitating disease (Arendorf & van der Ross 1996). This lesion is often overlooked as a lesion of potential candidal origin and is not always reported in the literature. The clinical diagnosis of angular cheilitis is simple as it presents extra-orally and can be observed through self-examination. This provides health care workers with the opportunity to educate their patients to look out for these lesions through self- examination.

5.2.2. Oral Hairy Leukoplakia

Oral hairy leukoplakia (15%) was classified into two types namely corrugated and non-corrugated form. The classic and predominant corrugated form presented in 13% of the sample, with 11% of the sample having lesions bilaterally. The non-corrugated form (2%), which is less obvious to the untrained eye and atypical in presentation, is often misclassified as a candidal lesion or white mucosal lesion (Begg *et al.* 1996). Studies reporting the clinical presentation of oral hairy leukoplakia (OHL) seldom make the distinction between the two forms. The non-corrugated form often goes undiagnosed, which in turn, affects diagnosis and staging of HIV disease. Both the CDC and WHO classification systems include hairy leukoplakia in determining the stage of the disease (i.e. presence of lesion indicates stage two or symptomatic stage) (WHO 1990; CDC 1993). Failure to diagnose these lesions would impact on appropriate management of the patient. This lesion is usually asymptomatic and evidence suggests that it is associated with the Ebstein- Barr virus (EBV) (Greenspan & Greenspan 1992).

The prevalence of OHL reported ranges between 3% to 44% (Shiboski 1997). This may be attributed to the varying composition of the sample (e.g. stage of disease), misdiagnosis (Greenberg, Thomas & Landesman 1992). Hairy leukoplakia has been observed in the advanced stage of the disease, reportedly, linked to HIV disease progression, namely the development of AIDS (Daniels et al 1987; Greenspan 1997). The WHO classification System weights the presence of oral hairy leukoplakia as a sign of AIDS in places where serological tests for HIV infection and CD4 cell counts cannot be done (Colebunders *et al.* 1987). In addition, variation in the reported prevalence may be due to misclassification where it may be incorrectly diagnosed as a candidal lesion or vice versa (Shiboski 1997). The prevalence of OHL may be over estimated in this study as the presumptive criteria according to the EC Clearinghouse guidelines were applied in conjunction with the response to antifungal therapy and/ results of candidal smears to eliminate

the possibility of a candidal lesion (EC-Clearinghouse 1993). Differences in the prevalence of hairy leukoplakia have also been reported to vary by gender and sexual orientation (Silverman, Migliorati & Lozada-Nur 1986; Shiboski 1997). Similar findings were observed in this study where hairy leukoplakia were more common in homosexual men.

5.2.3. Periodontal and Gingival Lesions

The prevalence of periodontal and gingival lesions associated with HIV infection observed in this study (20.5%) is similar to the findings of Lamster *et al.* (1994) in a study of homosexual men (21.3%) and intravenous drug users (39.1%). Variation in the prevalence of Necrotising (ulcerative) periodontitis has been reported to occur across racial groups in South Africa. Individuals classified as Coloured heterosexuals have higher rates than African heterosexuals (Arendorf *et al.*1997). The difficulty in diagnosing HIV-related Necrotising (ulcerative) periodontitis has been debated in the literature, since Necrotising (ulcerative) periodontitis also occurs in the general population and one needs to delineate the HIV-related Necrotising (ulcerative) periodontitis from type that occurs in the general population (Lamster *et al.* 1997). This can only be confirmed through longitudinal studies, where the baseline periodontal status of the subject prior to sero-conversion, needs to be established. Anecdotal evidence from patients does not suffice as alluded to in previous studies (Arendorf *et al.* 1998). The gold standard in measuring periodontal health requires an assessment of bone-loss and loss of gingival attachment, both of which should be confirmed with radiographic examination (Lamster *et al.* 1997). Hence, the findings in this study, as in the case of the other studies, are likely to be an underestimate of the true prevalence of HIV-related necrotising (ulcerative) periodontitis, as the diagnoses were made on clinical examinations measuring loss of attached gingiva and not with radiographs. For the same reasons, non-HIV-related periodontal lesions were not recorded in this study given the absence of definitive diagnostic criteria for the HIV-related periodontal diseases and absence of presumptive and definitive criteria for non HIV-related periodontal disease according to the EC-Clearinghouse guidelines (EC-Clearinghouse 1993).

The significance of detecting Necrotising (ulcerative) periodontitis and Necrotising (ulcerative) gingivitis in HIV persons is important, as it is usually observed in severely immune suppressed persons as well as

persons with a compromised nutritional status (Lamster *et al.*1997). In Africa, Necrotising ulcerative Gingivitis, particularly in children, has been reported even prior to the HIV epidemic, and malnutrition, compromised immune systems and high calculus and debris deposits were ascribed to the occurrence of these lesions (Enwonwu 1985). Soubry *et al.* (1995), in a study of Rwandan HIV positive adults and children showed that a strong relationship between HIV sero-positive status and the presence of Necrotising (ulcerative) periodontitis in both cohorts. They suggested that this lesion be used as an early indicator of HIV infection where the prevalence of HIV is high and diagnostic facilities are limited.

It important to note that not all severely immune suppressed persons will present with these lesions. It is not a robust prognostic indicator of immune suppression, but rather a clinical sign. The implications from a service delivery perspective, are that these lesions are preventable and treatable. Factors such as lifestyle, nutritional status, access to care and oral health status prior to infection are aspects that may influence the occurrence and progression of these lesions (Enwonwu 1985; Soubry *et al.* 1995; Lamster *et al.* 1997). Failure to treat these often painful lesions may affect the quality of life of those afflicted as disease progression may lead to severe pain, alter the aesthetic features and/ or compromise masticatory function. Emergency dental services should therefore be readily available (Phelan 1997).

5.2.4. Kaposi's Sarcoma

The prevalence of oral Kaposi's Sarcoma (2.5%) observed in this study was much lower than that reported by Jonsson *et al.* (1998), in a Zimbabwean cohort (72%), and Hodgson (1997), in a study of Zambian HIV-infected persons (8.4%). The high prevalence reported by Jonsson (1998) may be ascribed to a combination of selecting a sicker cohort since they examined cases referred to a *specialist* centre, and selection criteria as only subjects *with* oral HIV lesions. This may have led to an overestimation of Kaposi's sarcoma which is observed in advanced stages of HIV disease. The findings of this study are similar to that found by Arendorf *et al.* (1998), in a study of a South African cohort (1.5%) and Ramirez-Amador *et al.* (1998) in a Mexican cohort (3%). The presence of Kaposi's sarcoma is pathognomic of AIDS. Differences in prevalence have been described by geographic region (Wanzala *et al.* 1989) and sexual identity (Lamster *et al.* 1994). It is reported to be more prevalent in homosexual men compared to heterosexual IVDU (Lamster *et al.* 1994). The marked difference in prevalence seems to suggest that the underlying cause is possibly linked to a

sexually transmitted disease agent (Boschoff *et al.* 1997). The Kaposi's sarcoma associated Virus (KSHV) or the Human Herpesvirus 8 (HHV8) has been reported as the most likely etiological agent (Boschoff *et al.* 1997). Initially, the virus identified in KS was thought to be the Cytomegalo virus (CMV). Chang *et al.* (1996), observed a herpes-like DNA sequence and called it Kaposi's sarcoma- associated herpes-virus (KSHSV) which was later referred to as Human Herpesvirus 8 (HHV8). HHV8 is a gamma herpes-virus that is related to the Ebstein-Barr virus and HVS (herpesvirus *saimiri*); and has been implicated in the development of KS (Boschoff *et al.* 1997). The Human papilloma virus (HPV) and Herpes simplex virus (HSV) have been identified in KS lesions but not in KS cell lines, suggesting that these viruses are not associated with neoplastic cells in KS tissue (Monini *et al.* 1996). The HHV8 is not pathogenic in otherwise healthy individuals but is highly oncogenic in HIV-1 infected persons (Schultz 2000). A study examining the detection of HHV8-DNA in oral KS revealed that 53 out of 54 of the oral KS lesions has HHV8 (Flaitz *et al.* 1997).

Intra-oral presentation of Kaposi's Sarcoma is common, with 22% of persons first presenting with KS intra-orally and 45% of patients on the skin and intra-orally combined (Zakrzewska 1997). Oral KS is reported to be associated with lower CD4 cell counts compared to the cutaneous form (Orfanos *et al.*1995). Oral health care workers can play an important role in the early diagnosis of AIDS, as evidence shows that these lesions often manifest intra-orally and its presence is regarded as a diagnostic criterion for AIDS (Ebstein & Scully 1991).

5.2.5. Oral Ulcers

The prevalence of oral ulceration in this study was at the lower end (4.6%) of the range of 1% to 39.7% reported in the literature (Table 15). This is similar to the findings of Arendorf *et al.* (1998) at 2.9% and Hodgson (1997), who reported 4% in a Zambian sample. A wide range of etiological factors are attributed to these lesions and this poses a considerable management challenge to clinicians. To compound the problem, as many as 50% of ulcers are reported to have no clear etiological factor (Liang *et al.* 1994). Therefore, careful investigative procedures need to be followed as these lesions may cause extreme pain and often compromise patient's basic oral functioning such as mastication, speech and nutritional intake.

5.2.6. The Occurrence of Multiple Oral Lesions

Multiple oral lesions, defined as a single clinical type that occurs on *two sites (9%)* or the occurrence of two *different types* of lesions (42%) occurring simultaneously were observed in this study. Similarly, Tsang & Samaranayake (1999) reported 31.5% of HIV positive ethnic Chinese with multiple oral lesions, and Dodd *et al.* (1991), in a cohort of homosexual men (24%). A significant relationship was detected between the stage of disease/low CD4 cell counts and the occurrence of multiple types of lesions (p=0.002). This concurs with the findings in other studies of HIV-infected intravenous drug users (Shaikh 1994; Begg *et al.*1996). These findings seem to suggest that the degree of immune suppression is positively related to the occurrence of multiple lesions. The occurrence of multiple lesions is worthy of further investigation in cohort studies and it may have implications for predicting progress of HIV disease and may determine disease staging. This clinical sign, as an indicator of advanced stage of disease may be useful in settings where laboratory investigations are limited.

5.2.7. Sites of Lesions

The common sites where oral lesions presented were on the tongue (30%), angles of the mouth (29%), attached gingiva (29%) and floor of the mouth (8%). Previous studies of oral HIV-lesions have not reported this, hence, one is unable to make comparisons. The fact that most lesions were on the tongue and labial commissures suggest that early and easy detection is possible, as these sites are accessible even to an untrained eye. This may have practical implications for self-care or home-based care, where individuals through self examination or lay persons could be trained to detect these lesions.

5.3. OBJECTIVE TWO: THE DETERMINANTS OF ORAL HIV - RELATED LESIONS

5.3.1. Demographic Features of the Sample

The study sample comprised of mainly African, heterosexual, young adults who were unemployed and living in informal housing. The representivity of the sample by ethnic group and age mirrors the 1997

Provincial HIV antenatal survey, reflecting that young, African individuals were most affected by the HIV disease (Department of National Health 2000). The results showed that a large proportion were unemployed (44%), 91% had attained secondary level of education. The education levels of the sample was higher than the general provincial population (39%), while the unemployment rate compared poorly with the provincial figure of 18% (Statistics South Africa 1998). This raises the question whether unemployment was the result of the HIV-related illness or that unemployment being a risk factor for the disease. Medical insurance (6%) coverage was strikingly lower than that observed in the general population (28%) of the Western Cape (McIntyre 2000).

5.3.2. Clinical, Medical And Immunologic Profile

High-risk behaviour namely smoking cigarettes, alcohol consumption and daily intake of marijuana at the time of the study was evident. These factors are poverty-linked and associated with high-risk sexual behaviour such as unprotected intercourse (Suarez & Siefert 1998). The high prevalence of tuberculosis (25%) evident in this sample may be attributed to a combination of increased vulnerability to TB infection due to a compromised immune status. In addition, the Western Cape province has one of the highest prevalence of TB (699/100 000) in the world (Department of Health 1999).

Seventy six percent of the sample were currently taking medication, with antibiotic intake being most prevalent (46%). The high levels of antibiotic intake may be linked to the high tuberculosis prevalence and/ the prophylactic use of *Bactrim* for the prevention of PCP. One in every four of the sample reported taking traditional medications in conjunction with western medicines. This health -seeking behaviour is important to acknowledge as traditional healers can play an important role in the early diagnosis and referral of these patients.

5.3.3. Factors Contributing to the Occurrence of Oral Lesions

A myriad of factors such as environmental factors, lifestyle, sexual identity, access to health care, medical, nutritional or immunologic status may influence oral lesion presentation (Patton, McKaig & Eron 1998). As mentioned earlier, variations in the prevalence and clinical management of oral lesions related to HIV have been extensively reported in the literature.

However, few studies examined the determinants of these lesions (Table 16). This study focused on this aspect by integrating the clinical oral HIV presentation with a range of factors that may have influenced the outcome, such as, drug therapy, nutritional status, access to care, alcohol intake, smoking and poor oral hygiene. Meaningful comparisons of the oral lesion prevalence between various groups is hindered by variation in selection criteria and environmental differences. It is therefore important to control for these modifying factors when describing the determinants of HIV-related oral lesions. In this study, the correlates of disease were examined through bivariate and multiple regression analysis. The significant factors in the regression analysis were smoking, CD4 counts, access to care and calculus deposits. The ensuing discussion will focus on the findings of this study in relation to similar previously published work (Table 16).

5.3.3.1. CD4 Cell Counts

The study showed that, whilst controlling for a range of confounding variables, the odds of persons with CD4 counts of (≤200/mm) developing oral lesion/s were 2.07 (p=0.008) times greater than those with CD cell counts greater than 200/mm. These findings are consistent with previous studies that report the relationship between oral lesions and low CD4 cell counts (Table 16). Persons with single lesions had significantly (p=0.002) higher mean CD4 cell counts than those with multiple lesions (Table 5). This may have important clinical implications as these findings suggest that clinicians need to be vigilant of the possibility of HIV infection if multiple lesions are detected in an otherwise healthy adult. This could be the first step in the screening process, especially for developing countries where resources are limited. In settings where CD4 cell counts are routinely done, low CD4 counts could be used as a criteria for antifungal prophylaxis, entry into AZT trials or prophylactic oral hygiene measures (Lamster *et al.* 1994; Lamster *et al.* 1997). This group should therefore be targeted for early treatment, prophylaxis, prevention and removal of local irritants that may exacerbate the occurrence of HIV-related oral lesions.

The highest prevalence of lesions was found in the advanced stage of disease namely AIDS (82%) as opposed to 55% in stage one (p=0.00) (Table 6). These findings concur with studies examining the relationship between stage of disease and the presence of oral lesions (Swango, Kleinman & Konzelman 1993; Begg *et al.* 1996). This suggests that persons who reach an advanced stage of disease are more vulnerable to oral HIV-lesions.

Table 16. Review of Studies Examining Contributory factors Associated with Oral HIV-Lesions

Author Site	Design Analysis	Cohort	Prevalence of Oral Lesions	Most prevalent Oral lesions	Prevalence of oral candidiasis	Factors controlled for in the Analysis	Significant Factors
Lamster *et al.* 1994 USA	Cross Sectional N=160 Bivariate &Logistic	IVDU Homosexuals	69.6% 64.2%	IVDU OC 43 Homosexuals White Lesions 28	IVDU OC 43% Homosexuals OC .3%	CD4 Cohort Smoking Medication Alcohol Employment WBC	*Homosexual* Smoking Employment Antiviral CD4 , WBC, *IVDU:* None
Shiboski *et al.* 1996 USA	Prospective Multivariate N=218	Men & Women	22%	M HL 22% W OC 24%	OC 13% EC 3% PC 11% AC 2%	CD4 Race IVDU Gender	OC Gender, CD4 HL Gender,Cd4, Race
Patton, ***McKaig & Eron 1998*** USA	Cross Sectional N= 238 Bivariate & Logistic	Heterosexual Homosexual	48%	HL 26.5%	OC 20% EC 4.2% PC 14.7% AC 2.9%	Gender, Race CD4, Smoking Medications Oral health perception	All Lesions Race Alcohol CD4<200 OC Smoking, CD4
Ramirez-Amador *et al.*1998 Mexico	Cross Sectional N= 436 Bivariate & Logistic	HIV Positive Men & Women	75%	O C 38% HL 26%	OC 38% EC 26% PC 17% AC 10%	Gender, Age CD4, Stage Transmission Smoking, Medication	OC CD4 EC Gender HL Gender CD4
Palmer *et al.* 1996 UK	Cross Sectional N= 456 Bivariate & Logistic	HIV Positive Dental patients	AIDS 80% HIV 50%	HL 30%	OC NA EC 24% PC 11% AC 6%	Smoking Alcohol CD4 Medications	Smoking
Tsang & Samaranayake 1999 Hong Kong	Cross Sectional N=32 Bivariate &Logistic	Ethnic Chinese	75%	Minor ulcers 27.4	OC 2.3% EC 6.9% PC 5.5% AC NA	Age, Risk Group Identity, Medication, Vitamins, CDC stage, D4 count	Haemophiliac Bisexual AZT, Vitamins, CDC4 Antiparasitic
Matee, Scheutz & Moshy 2000 Tanzania	Cross –sectional N=192 Regression analysis	HIV negative and positive Adults	HIV 10.4% AIDS 36.8%	AIDS enlarged submandibular glands HIV 31% AIDS 29.6%		CD4 , Lymphocyte counts, disease stage	CD4 Stage
Current Study	Cross Sectional N= 239 Bivariate & Logistic	Heterosexual and Homosexual	68.6%	OC 46.8	OC 6.9% EC 8.9% PC 6.3% AC 7.6%	CD4, Age, Gender Cohort, Smoking Medication, Alcohol Race, Employment Oral Debris, TB	Smoking Calculus CD4<200 Access to health care

Key HL: Hairy Leukoplakia OC: Oral Candidiasis EC: Erythematous Candidiasis PM: Pseudomembranous Candidiasis M: Men W: Women IVDU Intravenous Drug Users

5.3.3.2. Smoking

A significant relation was found between smoking and the occurrence of oral HIV-related lesions. Those who smoked were 2.77 times more likely to develop oral HIV-lesions. Palmer *et al.* (1996) in a study of 456 HIV infected patients showed that smoking was the most powerful indicator of erythematous candidiasis and hairy leukoplakia through a multiple logistic analysis, adjusting for CD4 cell counts, alcohol and medication intake. This concurs with the findings of Lamster *et al.* (1994) and Patton, McKaig & Eron (1998), who showed that smoking was a significant determinant of oral HIV-related lesions. The effect of smoking on oral HIV morbidity is ascribed to changes in the local environment rather than on the immune system. Smoking is said to increase keratinisation of the mucosa, which possibly enhances the adherence of *Candida* to epithelial cells seen in smokers (Sweet, Challacombe & Naglik 1995).

5.3.3.3. Oral Debris and Calculus

The role of poor hygiene as a contributing factor in oral HIV-related lesions such as candida and periodontal lesions has been reported in various studies (Lamster *et al.* 1997; Rossi & Guggenheimer 1997). A study examining factors associated with HIV-related oral candidiasis showed that the presence of plaque was associated with oral candidiasis (Mc Carthy 1992). The present study showed that individuals with supra and /or subgingival calculus were more likely to have oral HIV-related lesions. Calculus may be a harbinger for opportunistic and anaerobic organisms. *Candida* together with atypical, often extra-oral pathogens (not usually found in periodontal disease) such as *Bacteroides fragilis and Fusobacterium varium, Fusobacterium necrophorum* and *Enterobacter cloacae,* are reported to occur subgingivaly and have been attributed to the unusually severe forms of HIV periodontal lesions (Lamster *et al.* 1997). The identification of novel organisms that resemble the *Clostridium villosum* in HIV-positive IVDU with poor hygiene and periodontal disease, further supports the needs to take into account individual lifestyle and habits of individuals when examining candidal and periodontal lesions (Lamster *et al.* 1997). African researchers such as Enwonwu (1985) and Soubry *et al.* (1995), ascribe poor hygiene with high calculus and debris, together with malnutrition, lowered immunity and exposure to endemic communicable diseases to the occurrence of necrotising ulcerative periodontitis and gingivitis. Oral care and preventative strategies should therefore take

into account local and systemic factors that affect disease in relation to the broader context such as poverty, access to care, oral hygiene practices and malnutrition.

5.3.3.4. Access to Care

There is wide consensus that disparities in access to health care across socio-economic groups impact on the health status of these groups (Ledergerber *et al.* 1998; Suarez & Siefert 1998; Weinreb, Goldberg & Perloff 1998). Utilisation and the provision of oral health services for the HIV-infected person has been examined extensively in the literature, but few studies have made the linkage between access to oral health care and the occurrence of HIV-related oral diseases (Patton, McKaig & Eron 1998). Locker (1993) has shown that health status is influenced by socio-economic and demographic factors; and they further explained that oral lesions related to HIV disease are influenced by environmental, socio-economic and demographic factors. Patton, McKaig & Eron. (1998) explained the low prevalence of oral HIV-related candidiasis as the result of good access to oral health care. In this study, poor access to oral health care was the most significant correlate of oral HIV disease in the final regression model. Whilst controlling for ethnicity, sexual identity and other variables, persons who had poor access to care were 6.36 more likely to have oral lesions.

There are diverse views about the methods of improving access to health care in relation to medical outcomes. Some argue in favour of achieving universal access to health care, whilst others recommend the need to focus on the broader socio-economic factors (Andrulis 1998; Pincus *et al.* 1998). Pincus *et al.* (1998) suggest that socio-economic differentials have widened despite the elimination of financial barriers. Alternatively, numerous studies showed that if financial barriers are levelled, health outcomes improved markedly in HIV-infected persons (Fenk 1998; Andrulis 1998). It is important to note that the above arguments should not be viewed separately, but that they are in essence, inextricably linked.

5.3.3.5. Other Factors

The findings of this study showed that ethnic status, gender, sexual identity (homosexual, heterosexual & bisexual), alcohol consumption, TB, antibiotic intake and age were excluded in the final logistic regression model, suggesting that they were not found to be significant contributory factors to disease after adjusting

for confounding variables. This is contrary to other studies reported in the literature and therefore they will be explored briefly in this chapter. The reasons for the variables not being retained in the model suggests that these factors were confounders and had an indirect relationship with the determinants of oral HIV-lesions. For example, gender appeared to confound the role of smoking as gender and smoking were found to be associated with each other and with oral lesions separately (Table 6 & Table 11).

The DMF score was not found to be a significant determinant of oral HIV-lesions. A study comparing DMF scores of HIV-positive individuals with the general population, showed no significant differences between the groups (Coates *et al.* 1996). Ethnic status was significantly associated with access to care and demonstrated a near significant relationship with oral HIV-lesion/s (Table 6 & Table 11). In the final model, after controlling for ethnic status and other factors (Table 6), access to care remained a determinant (Table 7). This highlights the need to examine determinants of oral HIV-lesions in a multi-dimensional manner, as there are many facets to the HIV-infected individual.

5.3.3.5.1. Medications

The use of antibiotics in moderating the prevalence of oral HIV-lesions is plausible. Antibiotic usage is reported to cause the proliferation of opportunistic organisms such as *Candida* (Rossi & Guggenheimer 1997). In this study, after adjusting for other variables, antibiotic use was not found to be significantly related to the oral lesions although it was significant in the bivariate analysis. Hence, the use of medications acted as a confounding factor. Similar findings are reported by Lamster *et al.* (1994); Ramirez-Amador *et al.* (1998) and Robinson *et al.* (1997). In contrast to this, Tsang & Samaranayake (1999) found that multivitamins and anti-parasitic drugs were significantly associated with oral lesions in a negative direction (protective effect). However, due to the small sample size of their study (n = 32), interpretation should be treated with caution as small sample sizes yield wide confidence intervals and may fail to detect significance for other contributory factors.

5.3.3.5.2. Xerostomia

Xerostomia was present in 6% of the sample, although it was not significantly associated with the occurrence of oral HIV-lesions. Xerostomia may arise from the use of antiviral drugs such as zidovudine, dideoxycytidene (ddc) and dideoxyinosine (ddi) and has been reported as an important risk factor for

candidal disease (Tsang & Samaranayake 1999). Saliva provides mechanical protection as a lubricant and a cleanser as it contains antimicrobial proteins such as histanins, which have potent antifungal activity (Fox, Neel & Leen 1991). In a study of 71 sero-positive persons with xerostomia, a positive association with HIV-related oral candidiasis was evident, whilst adjusting for drug usage, T4- count, age and race (Mc Carthy 1992).

5.3.3.5.3. Tuberculosis

Tuberculosis-related oral lesions have been reported to occur in HIV-infected persons in the form of tongue lesions (Ceballos-Salobrena, Aguirre-Urizar & Bagan-Sebastian 1996). In the present study, tuberculosis was diagnosed in 26% of the sample, with a positive association detected in the bivariate analysis between the presence of oral HIV-lesions and TB (p=0.00). However, a significant association was not detected in the final logistic regression. An incidental finding in the analysis was the significant relationship between the presence of erythematous candidiasis on the dorsum of the tongue and the presence of TB. One explanation might be that standard TB therapy requires 6-8 months of antibiotic therapy and prolonged antibiotic intake has been shown to be related to the occurrence of candida (Mc Carthy 1992). Persons with HIV and TB according to the WHO staging of diseases are classified as full-blown AIDS cases. These individuals are generally more immune suppressed and likely to develop opportunistic infections such as candidiasis. Tuberculosis is a disease of social deprivation and individuals are more likely to be nutritionally compromised. Hence, findings need to be evaluated further with TB patients as controls. Differences in presentation has potential implications for the early screening of HIV patients as the presence of erythematous lesions in TB patients may be an early sign of possible HIV infection. The question regarding the relationship between oral HIV-lesions and tuberculosis, which is in turn linked with malnutrition, prolonged antibiotic therapy and immune suppression, is raised. The findings in this study suggest that after controlling for a range of factors including medication intake, smoking, calculus and low CD4 cell counts, tuberculosis was not a significant determinant of oral HIV lesion/s. These findings suggest that TB is a manifestation of HIV infection as oral HIV-related lesions are. These manifestations may co-exist, interact and impact on each. From a service delivery perspective, it is important to note that individuals with HIV and TB, are placed on a prolonged course of antibiotics and have low CD4 cell counts. These individuals

can be targeted for prevention of oral HIV-lesions through oral hygiene education and health promotive strategies such as discouraging smoking and maintaining good hygiene.

5.3.3.5.4. Gender

Prevalence studies of oral lesions have shown gender differences in the presentation of oral HIV-lesions (Table 16). In this study, gender was significantly associated with oral lesions in the bivariate analysis with males being at greater odds of having oral lesions than females. In the final regression model however, gender was not retained as a significant predictor. This suggests that gender was a confounding variable and that it augmented the effect of another significant variable, leading to a mixing of effects. Shiboski *et al.* (1996), in a prospective study of 218 HIV-infected persons demonstrated that certain oral lesions such as oral hairy leukoplakia and oral candidiasis were more likely to occur in men than women after adjusting for CD4 cell count, race and intravenous drug use. The study of Shiboski *et al.* (1996), however, did not examine other possible confounding variables such as access to care and smoking, both found to be gender linked in this study (Table 11). As observed in this study, the South African Demographic and Health Survey (1999) revealed that more males smoked than females both nationally and in the Western Cape Province (SADHS 1999). This highlights the need to control for these factors when assessing the link between gender and oral HIV-lesions.

5.3.3.5.5. Race

The occurrence of HIV-related morbidity and mortality has often been described by differences across racial and ethnic groups in various studies in South Africa and abroad (Patton, McKaig & Eron 1998; Arendorf *et al.* 1997). Relatively higher levels of periodontal attachment loss has been reported in Black than in White HIV positive persons in the USA (Schenkein, Burmeister & Koertge 1993; McKaig *et al.* 1996). In a South African study, higher level of periodontal disease were reported in Coloured homosexual men than Black heterosexual men (Arendorf *et al.* 1997).

Ethnic status was inserted in the logistic model in the context of examining the role of this variable in relation to underlying factors that often confound the relationship between race and disease. These include factors such as housing, employment status and access to health care. The results showed that although in the bivariate analysis ethnic status was significantly associated with oral HIV-lesions, the variable was removed

in the final regression model after having controlled for a range of variables such as access to care, employment status, medication intake, gender and the presence of tuberculosis. This suggests that there were underlying variables that confounded the relationship between ethnic status and oral lesion.

This is contrary to previous work by Arendorf *et al.*(1997), where the authors alluded that ethnicity was a significant contributor to the occurrence of HIV-related oral lesions. However, these findings should be viewed with caution as there was no adjustment for possible confounding factors that may be linked to race and oral lesions such as access to care, employment status, presence of TB, poor oral hygiene and smoking. Explaining the differences in the prevalence of necrotising (ulcerative) periodontitis by ethnic groups where a link is made between 'race' and the presence of bacterial sub-gingival flora, as alluded by Schenkein, Burmeister, Koertge (1993) is to be treated.

It is known that in South Africa, inequity in health exists by race and gender because of the previous government's policy on resource allocation. This impacts on access to services. This is supported by the descriptive analysis of access to care, where access to health care varied by race groups (Table 11). However, in this study ethnic status was not retained in the final regression model and therefore this variable acted as a confounding factor in the analysis of the determinants of oral HIV-lesions.

5.4. OBJECTIVE THREE: ORAL HEALTH SERVICE UTILISATION AND ACCESS TO HEALTH CARE

The complex social, medical, psychological and financial needs of HIV-infected persons will place a huge demand for a range of social and health services (Kinghorn *et al.* 1996). In order to meet the need for oral health services it is important to understand the patient perceptions of their oral health status, the utilisation and access to oral health services.

5.4.1. Utilisation of Services

The majority of the sample examined sought care at the public sector clinics. This may be due to the fact that a large proportion of the sample were unemployed (66%) and only 6% had medical insurance (Table 2). Ten percent of the sample reported never having visited a dentist in their lifetime and over 70% having sought care only when they experienced pain. The high prevalence of emergency care visits reported in this study may be a reflection of poor access to preventative and routine care.

Participants reported that utilisation of oral health services were mainly for emergency care and not for routine treatment (Table 8). This concurs with the findings of Camara (1996), in a South African cohort where 64% reported they had extractions in their last visit and only 24% had fillings placed. Similar findings were reported by Markson *et al.* (1998) and Weinreb, Goldberg & Perloff (1998), where the lack of access to routine services contributed to the inappropriate use of emergency care in HIV-infected persons. This pattern of health seeking behaviour impacts negatively on service delivery in terms of increasing cost, compromises the quality of care and patient satisfaction. Studies examining health characteristics and utilisation of health services for HIV-care showed a link between frequent emergency visits and adverse health outcomes (Weinreb, Goldberg & Perloff 1998; Suarez & Siefert. 1998). The above suggest the need to improve access to oral health care and promote the practise of preventative health behaviour.

5.4.2. Oral Health Status Perceptions

The majority of the sample considered their mouths to be "very healthy" (60%) or "healthy" (22%), while 13% reported "some pain/ discomfort" and 5% perceived an "urgent need for oral care". (Figure 1). Therefore healthy as described by the participants was the absence of pain, discomfort and no need for dental care. Sixty percent of those who considered their mouths to be "very healthy", had HIV-related oral lesions, whilst 70% with some discomfort had lesions and all those who perceived an urgent need for care had oral lesions (Table 9). This suggests that there were two types of lesions namely symptomatic and asymptomatic. It also suggests that health was considered to be the absence of pain and the perceived need for care was influenced by the presence of pain (Table 8). This links with the findings reported earlier, that care is sought mainly for emergency pain relief and the notion of being healthy is the absence of pain. Sixty- eight percent of sample who perceived their mouths to be "very healthy" were from the category of secondary and tertiary levels of education. This suggests a positive relationship between oral health status (very healthy) and the level of education ($p=0.03$). In South Africa, education levels and ethnic origin are closely linked and the latter is shown to influence the perceived oral health status of individuals (Gilbert *et al.* 1994; Statistics South Africa 1998). The interaction of the three variables were controlled in the logistic analysis when examining the occurrence of oral lesions presence.

should include a better patient and provider awareness of HIV-related oral conditions. This should be promoted in conjunction with making treatment affordable and the expansion of dental insurance coverage.

5.4.3. Access to Care

Poor access to health care was the most powerful factor that influenced oral HIV diseases in this study, after adjusting for confounders such as educational level, ethnic status, gender, CD4 cell counts and medication intake. The major barrier to care reported by the sample was cost of care (33%). There are diverse views with regard to the elimination of financially based impediments as a measure to reduce the barriers. Some argue that reducing financial barriers would not affect the discrepancies in health outcomes as there are a combination of factors that interact. Andrulis (1998), in a review of studies on health insurance, access, outcomes and socio-economic status, concluded that the elimination of financially based barriers to care is central to create equity in health outcomes. The above arguments are relevant to the findings in this study, as only 6% of the sample had health insurance and the participants cited financial constraints as the major barrier to care.

Descriptive analysis examining factors associated with access to care showed that those without access to care were more likely to be unemployed, women and without medical insurance compared to those with access (Table 11). No significant relationship was detected between access to care and education levels. It is widely accepted that the HIV-infected groups of individuals carry a huge burden when seeking health care (Glick & Scuiba 1995). While many of the reported barriers in this study are not unique to this group, their HIV sero-status leads them to be a stigmatised and chronically ill group. This, together with the higher unemployment rates, does indicate that these individuals are marginalised and are disproportionately affected by the adversities of poverty.

5.4.3.1. Cost as a Barrier to Care

As alluded to earlier, cost of care (33%) was the major barrier. Terry *et al.* (1994) observed similar findings, where cost was cited as the predominant barrier to dental care by HIV-infected persons. This again links to the economic status of the sample. It may be argued theoretically that public sector services cost very little or are free in the case of primary care, and this should not deter utilisation of services. However, this does

not take into account indirect costs that the patient experiences such as transport costs and the loss of income if employed. The HIV-infected group has multiple costs as observed in this sample. Firstly, these patients attended a medical clinic where no formal dental care was offered and therefore needed to be referred for dental care to another site if the need arose. Some of the patients in this study had children who were HIV-infected, and health-care for the child had to be sought at a site 15 km away. It is important to consider the economic constraints placed on these individuals not only in terms of user fees, but factors such as time loss in seeking health care at different sites. Ideally, as in the case of comprehensive services, to reduce indirect costs to the patient, a person should be able to access various aspects of health care at a single site, on the same visit.

5.4.3.3. Third Party Payment Cover

Evidence both locally and abroad with regard to the deliberations of insuring HIV-infected persons show a widening of the gap between the insured and uninsured (Andrulis 1998). This was partly a result of a high level of intolerance to cost shifting both by payers and managed care providers. The outcome of cost shifting led to medical aid companies skimming off the healthy individuals as eligible members and health services creating disincentives for many providers to treat individuals without insurance. At the time of this study, the policy regarding protecting the HIV-infected persons from being denied medical insurance was not legislated. With the implementation of the Medical Schemes Bill in 1999, it will be important to monitor the effect of this policy.

The proportion of individuals who had medical insurance (6%) in this group was strikingly different to that described in the general Western Cape Community (28%) (McIntyre 2000). When stratifying the medical insured group versus the non-insured group in the study, many of the non-insured group were women (53%), unemployed (64%), had higher levels of oral diseases (88%), were smokers (37%) and only 8% reported access to oral health care (Table 11). Improved oral health care for HIV-infected persons should therefore include patient and provider education, affordable treatment and the expansion of insurance coverage (Greene *et al.* 1997).

5.4.3.4. Barriers to Care and Utilisation of services

Proponents of socio-economic reform argue that at a micro-level, other options need to be examined such as the manner in which services are utilised and encouraging patient self-management (Pincus *et al.* 1998). Indirect costs and the way health is prioritised by different groups may explain the differential utilisation of services by socio-economic groups. This is particularly relevant to this study, as it was shown that although individuals have oral lesions or symptoms, they did not always seek care.

5.4.3.4. Other Barriers to Care

Fear of pain (21%), rejection (15%) and infection (8%) were the most common barriers to care after cost (33%). Whilst 21% feared pain, it was pain that spurred the majority of participants to seek care. Dental visits are therefore associated with pain. This incongruency seems to suggest an element of avoidance behaviour. Studies of HIV-infected women in the USA reported similar barriers such as fear of rejection, pain, discomfort with dentists, not knowing which dentist to visit, a perception of poor oral health and financial constraints (Shiboski *et al.* 1999; Weinreb, Goldberg & Perloff 1998).

Other barriers reported in this study included long waiting time (8%), language barriers(8%), too far (8%) or not knowing where to seek dental care (8%). The study by Camara (1996) further supports the above findings where 57% of a sample HIV-infected South Africans revealed that they would prefer to attend a private dental clinic than the public sector clinic due to reduced waiting times, easier access, and flexible times for service provision compared to the public sector.

5.5. OBJECTIVE FOUR: THE PROVIDER PERSPECTIVE ON THE DELIVERY OF ORAL CARE

5.5.1. Comprehensive Care versus Dedicated Clinics

There was unanimous agreement amongst the health care workers that oral health care is an important component of the comprehensive service for HIV-infected persons and that care should be provided at all levels of care. The report by the clinical staff about not being appropriately resourced to carry out universal

precautions is worth noting. This observation is supported by the findings of Rudolph & Ogunbodede (1999), where oral health clinicians from the public sector reported barriers to carrying out infection control as; gloves not sufficient for changing after every patient (21%), insufficient/unavailable disinfectants (22%), no autoclave (11%) and no special waste disposal systems (15%). Theoretically, all the public sector clinics should be equipped with appropriate infection control resources such as autoclaves, protective gear, disinfectants and sufficient instruments.

Comprehensive care was the favoured method of delivering oral care in this study. Contrary to these findings a study of dentists in the UK showed that 95% of the sample felt that HIV-infected persons should be treated only in dedicated clinics (Gibson & Freeman 1996). One of the reasons cited in favour of dedicated clinics was that the existing primary care centres were not adequately resourced to deliver these services. In response to the latter, Glick & Burris (1997), asserted that the vast majority of oral health services required by HIV-infected persons were routine dental care, within the realm of a general practitioner. They suggest that the primary care physicians can play an important role in the prevention of diseases, in the early detection of disease, alleviating symptoms and in the referral to other health care services. The role played by dedicated clinics is certainly not to be overlooked as the proponents have pointed out. It is suggested that unusual and complex cases may be referred to the dedicated clinics and these centres may play an advisory and training role (Glick & Scuiba 1995). In the South African context, the arguments of Glick and Burris (1997) are relevant in that all health care workers should be able to treat routine HIV-related conditions given the high prevalence of HIV infection. Every patient should be considered a potential HIV positive patient and therefore infection control measures should be universally applied and management of primary level care should be considered routine practice.

The HIV epidemic in South Africa is the fastest growing in the world and therefore is a serious public health issue. With a growing number of infected persons, dedicated clinics may not be the only option for the delivery of oral health care. The reality is that care for HIV-infected persons will have to extend to broader comprehensive dental services; private practices and home –based care in order for it to be accessible and affordable. Dedicated clinics could continue to play an important role in the delivery of specialised care and act as training sites for health care workers (Glick & Scuiba. 1995).

5.5.2. Care Provider Concerns and Fears

Poor adherence to the protocol for the management of needle-stick injuries is similar to the findings observed by Shaikh, Harnekar & Moola (1998), in a study of oral health workers. The previous study revealed a prevalence of needle-stick injuries of 32%, with only 15% of the injuries being reported. While the risk of transmission through needle-stick injuries is small (Beekman *et al.* 1990), the expressed fear and anxiety experienced as the result of the injury needs to be addressed in a sensitive manner.

The perception of having inadequate skills to treat HIV-infected lesions is not unique in this setting, but expressed universally (Darling, Arendorf & Samaranayake 1992; Gibson & Freeman 1996; Glick & Burris 1997; Shaikh, Harnekar & Moola 1998; Rudolph & Ogunbodede 1999). Lessons can be learnt from other countries in that training and education are essential for the alleviation of misconceptions, ignorance and phobia. A study in the UK showed that dentists' scientific information helped alleviate their concerns about the infection transmission (Gibson & Freeman 1996). The concerns and fears of HIV-infected patients regarding seeking treatment may be linked to patient perceptions of dentists not willing to treat them due to their HIV-status. This theory is supported by a study examining utilisation of dental services by HIV-infected persons, where despite a high level of attendance before their HIV diagnosis, 60% did not attend after diagnosis (Robinson & Croucher 1993). Of those individuals who visited after being diagnosed, 75% reported that they had been refused or deterred by oral health staff and 15% said that they did not disclose their HIV-status for fear of being rejected (Robinson & Croucher 1993).

The perceptions of patients that dentists are unwilling to treat HIV persons, and the reported behaviour of dentists unwilling to treat HIV-infected persons act as important barriers to care. The proponents of dedicated HIV oral health clinics support the view that these clinics act as an important safety-net for HIV-infected persons (Glick & Scuiba 1995; Croucher *et al.* 1997). However, the difficulties surrounding the care of HIV-infected persons should not be underestimated. Traditional dental education does not teach oral health personnel how to deal with death, or dying patients (Glick & Scuiba 1995). Dentists often work in isolation and there is an absence of professional support structures as found in university settings and hospitals (Glick & Scuiba 1995). Hence, there is a need to bridge these gaps through continuous professional education. In South Africa this can hopefully be addressed through the introduction of the mandatory Continuous Professional Development System.

5.6. OBJECTIVE FIVE: ESTIMATE THE COST OF DELIVERING ORAL HIV CARE

The two key factors central to the planning of health services is to take into account the demand for care and the cost of the service. In South Africa, this has become particularly relevant since the health reform strategies were implemented by the new government in 1994. The allocation of resources has been largely budget-driven and based on historical spending. The HIV epidemic will certainly impact on the planning and allocation of resources in the public health sector because of the growing number of HIV patients seeking care. A phenomenon described in the early stages of the epidemic as "crowding out" of non-HIV-infected patients, has now become a reality in the public health hospitals (Hassig, Perriens & Baenda 1990). Hence, in order to provide appropriate care to HIV-infected persons, accurate information on the cost of care is necessary (Kinghorn *et al.* 1996).

Projections on the estimated costs of care suggests that health care costs for HIV-infected persons will consume between 19% and 49% of the total health care budget by the end of year 2000 (Doyle *et al.* 1991). Accurate assessment of costs however, is hindered by the scarcity of reliable data on the clinical costs of care (Kinghorn *et al.* 1996). This makes it difficult to extrapolate cost per case or visit as the epidemic progresses (Hussey, Robertson & Beatty 1992; Taylor 1992). Furthermore, most of the studies have focussed on HIV-inpatient care and less emphasis has been placed on outpatient care, particularly for oral health care of HIV-infected persons. The direct costs of oral health services were extrapolated from clinical data at an HIV outpatient clinic. Since costing was not a central theme of this study, the analysis is crude and the purpose was to link this to the issue of delivery of oral health services. The data does however, provide baseline information necessary for projecting potential costs of HIV care in the public sector. This study revealed that professional costs (consultation and oral health education procedures) formed 62% of the total cost. This was followed by drug costs at 23%. The average cost per visit (R130.73) did not fluctuate significantly by disease stage, although there was a tendency to increase at stage three of the disease. This can be explained by the fact that oral lesions are present throughout the stages of HIV disease, with an increase in the frequency and severity as the disease advances.

The average cost per event was calculated given that the data was cross-sectional. The assumptions regarding the prevalence were drawn from this and previous work (Arendorf *et al.* 1998). Assuming that 60% of the sample will develop oral lesions per annum, the extrapolations showed a rising trend of oral health care costs as the prevalence of HIV increased. The assumption of utilisation patterns was based on the findings of this study sample, which suggested that 30% would seek care if they had oral lesions at a given point in time.

It is important to note that these figures are estimates and as the HIV epidemic matures, a larger proportion of individuals will enter the advanced stage of disease. The cost of treating certain lesions such as candida would increase, due to the use of more expensive drugs for more severe forms of disease as demonstrated in a study of medical outpatient HIV-infected persons in Gauteng, South Africa (Kinghorn *et al.* 1996). The results of this study showed that over a period of four years, the provincial allocation for oral health care in the public sector facilities did not increase at the same rate as the estimated cost of HIV-related oral care.

The limitations of this costing study are recognised as there are difficulties in generalising from a single study site. These estimates are approximations, as the average cost and not the actual cost was used. Furthermore, the cost may be an underestimation of the actual cost as the result of drug prices being lower in the state institutions since they are bought on tender as well and the laboratory cost varying between laboratories. However, it does demonstrate that the trend in increased morbidity does not correspond with the trend in budget allocation for public sector facilities. However, many of these lesions are easy to diagnose and treatment of these lesions need not be expensive. These lesions can be treated in primary health care settings in the public sector with hygienists and therapists treating some of these lesions at a lower cost. Furthermore, emphasis should be placed on home care and encouraging health promotive behaviours such as maintaining good hygiene and removal of local irritants.

5.7. STRENGTHS AND LIMITATIONS

The limitation of potential selection bias in this study is noted. It can be argued that a sicker cohort is more likely to attend a hospital outpatient clinic. Preliminary analysis of the profile of the patients attending the clinics showed an even spread of case-mix by immune status and disease stage. Observing healthy controls

was seriously considered. However, due to limited resources and logistical problems characteristic of over-burdened state services, this was not feasible in this study. However, it is important to note that these patients sought medical care and not oral health care. The patients were not chosen on the basis of their oral health status, treatment history, or their immune status, hence the reduction of selection bias.

The sample representivity was interrogated by examining the population breakdown by race from the HIV antenatal study. The findings in this study concurred with the antenatal study where the predominant population affected were African, heterosexual females in the age group 20-39 years. Given the focus on heterosexuals attending the hospital, the results may not be generalisable to the broader community. However, studying this population is relevant, given their increased vulnerability to contracting other infections and the possibility of developing severe complications. This information may provide an in-depth understanding of oral manifestation in HIV persons in a hospital setting. Hence, with better understanding, appropriate care and early intervention may be improved.

Certain information provided by the patients may have been subject to bias, given the sensitive nature of this research. There might have been an under-reporting of alcohol intake, smoking or an over reporting of health service utilisation in an attempt to please the examiner. A clinician trained in HIV management conducted the structured interviews. The information was verified with other sources of information e.g. social worker reports and medical files. Participants were also informed of the importance of participation and were reassured of confidentiality. The participants were referred for counselling during the course of the study if the need arose. In addition, oral health care was provided to the participants.

The author recognises the limitations of this study with regard to the measurement of HIV-related periodontal lesions as described by Robinson (1998). At the time of the study there were no clear EC–Clearinghouse guidelines with regard to the definitive diagnosis of these lesions and hence it was based on the presumptive criteria as defined by the EC-Clearinghouse group (EC-Clearinghouse 1993). However, clearer protocol criteria have been proposed since the time of this study by Robinson (1998) and it would be important to consider the recommendations of Robinson (1998) with regard to the measurement of these lesions for future studies.

Whilst non-corrugated leukoplakia on the lateral border of the tongue and Median Rhomboid Glossitis does not form part of the EC-Clearinghouse guidelines, the author felt that it was important to note these lesions

in an African cohort in order to compare these findings with other studies reported previously. It is important to note that the EC-Clearinghouse guidelines were formed on the basis of findings of previous studies and are subject to change with emerging and relevant information from various parts of the world.

It is acknowledged that due to limited resources, complete histological investigations could not be undertaken for the diagnosis of certain lesions such as hairy leukoplakia and Kaposi's sarcoma and this may have lead to an over estimation of lesion prevalence. However, the presumptive criteria according to the EC Clearinghouse were strictly adhered to.

One of the limitations is the inability to cost the services in a comprehensive manner with indirect costs and capital costs taken into account. This aspect was considered, however, given the extensive nature of this task, it was beyond the scope of this study. These figures are essentially estimates of the cost of an average oral health visit for the years 1996-1998. The prices quoted for drugs bought at state tender prices and it is acknowledged to be lower than the market value in the private sector. Laboratory costs may also vary between laboratories. These factors most likely contributed to an underestimation of the true cost. Both the upper and lower estimates on the other hand, may be inflated by the lack of alternative and potentially cheaper services in the primary health settings. However, the study reinforces the indication given by the average cost per visit, of the potentially huge cost implications of the epidemic. It highlights that the rising costs should be matched by allocation of resources.

Essentially, there are several aspects of this study that make it unique both in Africa and internationally. Firstly, a comprehensive approach was undertaken in the examination of oral health for HIV-infected persons. It focused not only on clinical features, but also examined service delivery and broader socio-demographic factors as such as barriers to care, utilisation of oral health services, oral health behaviour of infected persons, employment status, housing and education. The clinical outcome was analysed by taking into account potential confounders and effect modifiers such as smoking, employment status, gender and alcohol intake. In addition, the provider perspective, patient experiences and opinions were examined to gain a better and meaningful understanding of service delivery issues. This entailed the examination of attitudes, perceptions and the experiences of the clinicians. The information may provide an in-depth meaning for the development of intervention strategies.

The range of African studies that have examined determinants of oral HIV-lesions focused predominantly on medical and demographic factors through bivariate analysis. This study aimed to analyse the data through a multivariate analysis taking into account a broad range of factors that may have influenced the outcome such as clinical, socio-demographic and medical variables. Studies that examine oral HIV-lesions in relation to other factors through bivariate analysis run the risk of drawing hasty and artificial linkages to variables such as ethnic status, gender and age. Ethnic status, particularly in South Africa, is closely linked to socio-economic status and there is the danger of mixing of the effects in the absence of analyses that adjust for the confounding and intervening variables. Bivariate analysis is limited, in that it provides a description of the clinical presentation of oral lesions in a two dimensional manner (TB versus oral lesions, alcohol intake versus oral lesions). It does not examine how all these variables simultaneously contribute to the occurrence of oral HIV-disease. Multiple logistic regression analysis allows for a three dimensional analysis, whereby all other potential confounding variables are controlled for, when measuring the impact of a single contributory factor. From a clinical management perspective this information may be useful in guiding the clinician in management strategies such as discouraging alcohol consumption and placing individuals on prophylactic antifungal therapy when prescribing long term antibiotic therapy in HIV-infected persons. From a public health perspective, this form of analysis is important so that intervention strategies can be developed from evidence, based on a spatial analysis. These results suggest that potentially promising intervention opportunities may exist in reducing oral morbidity related to HIV-infection and are worthy of further exploration. These include broad public health and individual intervention strategies such as discouraging smoking, improving access to care and promoting good oral hygiene in HIV-infected persons. These results suggest that ethnicity, gender and TB are inter-linked with factors such as access to care and smoking and strategies for prevention should be explored with key intervening variables in mind as the prime focus.

Secondly, the sites of the oral lesions were recorded, unlike previously reported studies. The findings in the current study showed that lesions were located on sites such as the tongue, corners of the mouth, which may be accessible even to the untrained eye. Therefore this suggests that self-care and home-based care programmes should include training on the detection of these lesions. Multiple lesions in this study was significantly associated with low CD4 cell counts, highlighting that the occurrence of these lesions may act

as early indicators of advanced stage of disease and provide early opportunity to intervene with prophylactic measures.

Thirdly, while there has been an abundance of information on the cost of medical HIV care, none have been reported on HIV-care in the oral health sector, except as part of the medical component, where the cost of specific oral lesions such as candidiasis is noted (Kinghorn *et al.* 1996). However, in the previous study, medically trained individuals diagnosed the oral lesions and the literature has shown that medical examiners are less successful in diagnosing oral lesions (Cruz *et al.* 1996). This may then lead to underestimation of oral morbidity and subsequently of cost of care.

The findings of the qualitative component examining health care worker perceptions with regard to the delivery of care were exploratory. No inferences can be made from these findings although they confirm the findings of previous studies which showed there is a need for training and to ensure adequate resources are made available to improve access to oral health services (Rudolph & Ogunbodede 1999).

Caution is required when interpreting these findings as a cross-sectional study cannot demonstrate cause and effect. Longitudinal analysis is required to further investigate the hypothesis generated in this study. This study however, raises an important hypothesis, namely that oral lesions in HIV-infected persons can be reduced through health promotive and preventive measures. These include micro and macro level interventions of reducing local irritants and improving access to care. There is the potential to reduce exposure to oral debris and smoking, which were important contributors to the occurrence of HIV-related oral diseases. In an environment of increasing HIV-morbidity and scarce resources, it is also important to educate individuals with regard to self-examination, self- care and to be vigilant of lesions requiring prompt treatment. At a macro level, there is a need to improve universal access and improve social and economic conditions.

5.8. SUMMARY

This study has shown that certain oral lesions are common in HIV-infected persons. It has also highlighted that the prevalence of oral lesions related to HIV infection may vary by different cohort. This variation may be attributed to a range of factors such as sample selection, environmental, social, local, medical, demographic factors and access to dental care.

The significant determinants of oral HIV-lesions were reduced immune status, smoking, the presence of calculus and poor access to care.

Financial constraints and fear of pain or stigma, influenced patterns and frequency of service utilisation. The general consensus amongst HCW on the comprehensive delivery of care is positive, although there remain huge challenges, in translating these sentiments into action. The dissonance between clinicians and policy makers is of concern and requires exploring methods of improving communication and engendering a common vision. The cost of oral HIV care was analysed, suggesting that as the epidemic matures, the increased need for oral health care would have to be accounted for in the allocation of resources.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1.Conclusions

The purpose of this study was to examine the prevalence and determinants of oral lesions related to HIV infections and it's implications for service delivery. The demographic features revealed that the large proportion of individuals affected by HIV epidemic were young, African, heterosexual, unemployed individuals, who are also considered to be the most marginalised sector in South Africa.

Oral lesions related to HIV infections presented in 68.6% of the sample, with candidal lesions most prevalent. The oral lesions were located mainly on the tongue, angles of the mouth, attached gingiva and unattached mucosa. A significant relation was detected between the presence of multiple oral HIV lesions and disease stage, with individuals in the advanced stage of disease having a higher prevalence of oral HIV disease.

The significant determinants of oral lesion in the multivariate analysis were poor access to dental care, smoking, calculus and CD4<200. Factors such as age, gender, alcohol intake, medication intake and ethnic status that were significant in the bivariate analysis were excluded from the regression model in the multivariable analysis. These factors therefore acted as confounding factors in the bivariate analysis. It highlights the importance of spatially examining determinants of oral HIV-related disease when explaining variations in subgroups.

The occurrence of multiple lesions in patients with low CD4 cell counts suggests that these manifestations can be used as early indicators of disease progression. The location of lesions on sites that are accessible to the untrained eye raises the possibility of self and home-based care interventions.

The findings highlight the importance of targeting individuals who are likely to be at risk of disease with micro and macro-level public health interventions. These include improving universal access to care, promoting appropriate health- seeking behaviour, removal of local irritants, promoting the practise of oral hygiene, discouraging smoking and introducing prophylactic care to those with lowered immune status.

The patient perspective of oral health service utilisation revealed that a majority of the participants had poor access to health care. Individuals sought care mainly at public health services and predominantly for emergency care (extreme pain or dysfunction). Of those who considered themselves to be very healthy, 60% had oral lesions. All those who expressed an urgent need for care reported experiencing pain and had oral HIV-lesions. The findings suggest that health was associated with an absence of pain. Ninety one percent of the sample reported to have experienced barriers to oral health services, with cost, fear of pain, fear of rejection or stigma being most dominant.

The majority of health care providers were in favour of comprehensive clinics. They reported that this would improve access to health care, reduce stigma and is in line with the broader health reform strategy in South Africa. However, they recognised the role dedicated clinics perform as training sites and referral sites for complex cases.

Seventy-three percent of the oral health workers felt that their working environment did not enable them to carry out universal precautions. Reservation to treat HIV patients was driven mainly by the fear of being infected through needle-stick injuries. They also raised concerns that the health service managers were not sensitive to the difficulties they faced at the coal face of health care delivery.

The cost analysis showed that the average cost per visit was R130.73, with the rates of projected oral health costs increasing more rapidly than that allocated by the provincial health department. These estimates suggest that the demand for care would place a huge burden on health care services as the HIV epidemic matures in South Africa. It is in this light that the following recommendations are made.

6.2. RECOMMENDATIONS

1. To develop strategies to improve access to dental care services for HIV-infected persons.
2. To develop methods of improving the referral system and information transfer system at various levels of care.
3. To perform an audit of public oral health facilities, specifically examining the equipment and materials in terms of enabling the practise of universal precautions for infection control.
4. To perform a detailed analysis of the marginal cost of treating oral HIV-lesions.
5. To inform managers of the potential cost implications and its impact on planning health services.

6. To explore methods of enabling oral home-based care and self-care for HIV-infected groups.
7. To include in general health promotion messages the importance of good hygiene, non-smoking and health seeking behaviour.
8. To train service providers in infection control, early diagnosis and appropriate management of oral HIV diseases.
9. To target oral health care workers for training through the motivated continuing education for accreditation purposes.

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Appendices

1. Consent Form and medical questionnaire
2. Oral examination questionnaire
3. Oral health service utilisation questionnaire
4. Calibration
5. EC-Clearinghouse Guidelines
6. Qualitative study questionnaire
7. Cost Estimates
8. Photographs of Oral HIV-related Lesions

Appendix One: Consent Form and medical questionnaire

:ONSENT TO PARTICIPATE IN A RESEARCH PROJECT

'urpose and procedures

:his study looks at ways of improving early diagnosis of disease and :acilitating better oral health services for HIV infected persons. The study will involve several parts. First you will be asked some questions in privacy for about ten minutes.
There are no right or wrong answers. You may refuse to answer any question at any time without penalty. After the interview I would examine your mouth and perhaps with your permission take some pictures of your mouth.

I would assess the condition of your mouth and advise you . After being involved in the first interview, you will be asked to attend this session every six months for a year. The session will last about fifteen minutes.

Risks
Being involved in the study, you my feel that other persons in the clinic will think that you have a worse disease than they have. However, in doing similar work else where, patients said that after the research began other patients wanted also to be part of the study. You may feel uncomfortable or nervous when you answer sensitive question, but you may choose to not answer any questions that make you feel this way.

3. Potential benefits
You will be given a free oral examination and if there are sores in your mouth, rotten teeth or if you experiencing any discomfort I will advise you and arrange treatment for you. Being involved in this study, you can help us develop better ways of helping persons with HIV related oral diseases as well assist us in understanding the disease.

4. Alternative procedures.
It is unlikely that you will miss any of the other activities in the clinic by being involved in the study. You are also free to get any other services in the clinic on your own at any time.

4. Confidentiality .
All information you give to us in this study, including the examination will be kept confidential. We will not discuss anything you consider confidential with other individuals. The answers in form will not be linked to your name. Instead we will use a code. I will be the only person in possession of the list linking your name to the results.

6. Compensation
If you have severe sores or require urgent dental care I will ensure that you receive such care. Transport cost to attend the second, third and subsequent visits will be covered.

7. For more information.
If you have any question about being involved in the study please contact Najma Shaikh who will be in this clinic.

8. Participation
To be involved in this study, you need to sign this form. You can withdraw from the study at any time without penalty.

I have explained to the participant, who has received answers to all questions posed. To the best of my knowledge, s/he understands and is competent to give informed consent.

.....

Najma Shaikh
Principle investigator Columbia university, division of Epidemiology, school of Public Health, New York.

I have read the above statement, and have been able to ask any question. I agree to be involved in this study.

....
Signature (participant) Date

)RAL MANIFESTATION OF HIV/AIDS IN A HETEROSEXUAL COMMUNITY

1.Subject ID

2.Visit#

3. Calibrated 1. yes 2. no

4. Date of visit

5. Cohort
   a. S.West
   b. GSH
   c. other

6. Ethnic Group
   1. white
   2. Indian
   3. mixed
   4. African

7. Reason for attending the clinic
   1.Routine examination
   2.Emergency
   3.Referral due to HIV symptom
   4.other

8. Occupation
   1. Unskilled
   2. semi skilled
   3. skilled
   4. Minor professional
   5. professional
   6. other, specify .....

9. Employment Status
a. 1. yes 2. no

b. If yes, length of time (months) unemployment.....

10. Housing
   1. domiciled
   2. living in a shack
   3. shelter
   4. prison
   5. other ...specify.....

11.Education in years

12. HIV Status
    1. confirmed pos
    2. Presumed pos
    3. Neg
    4. Unknown

13. Date confirmed.

14. Suspected mode of transmission
    1. Sexual contact
    2. IVDU
    3. Blood Transfusion
    4. perinatal
    5. unknown
    6. other .....specify.....

SMOKING/ILLICIT DRUG USAGE

15a. Do you smoke regularly (at least one cigarette per day) 27
    1=yes
    0=no (go to ques #17)
    8=N/A (go to ques #17)
    9=UK(go to ques #17)

15b. For approximately how many years did you smoke?

15c. How many cigarettes do you smoke regularly per day(Go to #16)

16 a. In the past did you smoke cigarettes regularly?
    1=yes
    0=no (go to ques #17)
    8=na (go to ques #17)
    9=uk (go to ques #17)

16b. Approximately how many years did you smoke?
    a.
    b.88=n/a
    c.99=uk

16c. On average, during the time that you smoked, how many did you smoke?
    a.
    b.88=nk
    c.99=uk

17a. Do you chew tobacco or snuff
0=no (go to #18)
1=yes
88=na(go to #18)
99=uk (go to #18)

17b. On average how many times a week do you chew tobacco ?
a.
b.88= DNA
c.99= UK

18. Currently, how often do you have a drink containing alcohol, whether it's wine, beer, liquor?
1. 3 or more times a day
2. two times a day
3. once a day
4. nearly every day
5. three or four times a week
6. once or twice a week
7. two or three times a month
8. once a month
9. less than once a month but at least once a year
10. once a year
11. abstinent

19. If abstinent, how long have you been abstinent?(# of months)36

20. Was there a time in your life when you drank daily?
1. yes 2.no

21. Think of the time that you have drinks containing alcohol recently
How often did you have as many as 5 to 6 drinks
1. nearly every time
2. more than half the time
3. less than half the time
4. once a while
5. never

22.Think of the time that you have had drinks containing alcohol, how often did you have as many as 1-2 drinks?
1. nearly every time
2. more than half the time
3. less than half the time

4. once a while
5. never

23. When is the last time you used each of the following recreational drugs

KEY
0. none
1. in the last 24 hrs
2. in the last week
3. last month
4. last 6 mnths
5. more than six months ago
6. DNA
7.UNKNOWN

a. Marijuana. ☐

b. Mandrax. ☐

c. cocaine ☐

d.other ☐

24.Do you take any other forms of alternate medication? ☐

1.Sangoma's
2.vitamins
3.other(specify).....
4. no

MEDICAL HISTORY

1.Subject ID

2. Date of last visit

3. Examiner.....

4. Date of birth

5. Gender 1. female 2. male

a. Are you pregnant

a. Do you use birth control pills ?

c. Are you currently nursing

6. History of illness Key 0= no
1=.yes, now
2=yes, 6mnths ago
3=yes, over 6 mnths ago
4=n/a
5=don't know

a. Tuberculosis

b. Herpes Simplex

c. Herpes zoster (shingles)

d. Pneumonia(PCP)

e. Oral Hairy Leucoplakia

f. MAI(Myobacterium Avium Intracellulare)

g. Wasting

7. Cancers

a. Kaposi's sarcoma

b. lymphoma

c. cervical cancer

d. minor mucocutaneous

e.other.....

8. Have you ever had

a. head /neck radiation therapy

b. chemotherapy

c. surgery

d. other .....

9. Syphilis
1.yes 2. no
if yes , how many times.....

10. Gonorrhoea
1. yes 2. no
if yes , how many times.....

11. venereal Warts
1. yes 2. no
if yes , how many times.....

12. Herpes a. labialis

b. genital herpes

13. candidiasis

a. oral
If yes specify site/s.....

b. Oesophageal
If yes specify site/s.....

c. Vaginal

14. Salmonella

15. Any blood diseases?

a.salmonella septicemia

b.pneumococcal septicemia

c. ITP

16. CD4 COUNT
    a. percentage.....
    b. raw.....

17. CD8 COUNT
    a. percentage.....
    b. raw.....

18. CD19 COUNT

    a. percentage.....
    b. raw.....

19. WBC COUNT(X104).....

20. STAGING

a. CDC

b.WHO

21. Are you circumcised
1. yes 2. no

22. Preferred sexual identity

Center for Oral HIV Studies

MEDICATION USAGE

1. Subject ID [ ][ ][ ][ ][ ][ ] 1-6

2. Dental visit# [ ][ ] 7-8

3. Today's date (mo/day/yr) [ ][ ][ ][ ][ ][ ] 9-14

4. Examiner's initials..... [ ][ ] 15-16

5. Date of birth [ ][ ][ ][ ][ ][ ] 17-22

6. Subject taken any medications in last 6 months? [ ] 23

   1. Yes 0. No

   a. currently taking
   b. within 1 week
   c. within 2 weeks
   d. within 1 month
   e. within 3 months
   f. within 6 months

	CODE	NAME	WHEN		
24-25	a.	.....	.....	.....	1 2 3 4 5 6 [ ]
27-28	b.	.....	.....	.....	1 2 3 4 5 6 [ ]
30-31	c.	.....	.....	.....	1 2 3 4 5 6 [ ]
33-34	d.	.....	.....	.....	1 2 3 4 5 6 [ ]
36-37	e.	.....	.....	.....	1 2 3 4 5 6 [ ]
39-40	f.	.....	.....	.....	1 2 3 4 5 6 [ ]
42-43	g.	.....	.....	.....	1 2 3 4 5 6 [ ]

45-46	h.	.....	.....	.....	1 2 3 4 5 6		4
48-49	i.	.....	.....	.....	1 2 3 4 5 6		5
51-52	j.	.....	.....	.....	1 2 3 4 5 6		5
54-55	k.	.....	.....	.....	1 2 3 4 5 6		5
57-58	l.	.....	.....	.....	1 2 3 4 5 6		5
60-61	m.	.....	.....	.....	1 2 3 4 5 6		6
63-64	n.	.....	.....	.....	1 2 3 4 5 6		6
66-67	o.	.....	.....	.....	1 2 3 4 5 6		6

Appendix Two: Oral examination questionnaire

Center for Oral HIV Studies

Medical Staging

. Subject ID ___ ___ - ___ ___ ___ ___ - ___ ___
. Dental visit # : ___ ___
. Today's date (mo/day/yr) ___ ___ / ___ ___ / ___ ___
. Examiner's initials ___ ___ ___
. Date of birth ___ ___ /___ ___ /___ ___
. Removable dentures present?..... Yes 1 No 0
Circle: FU, FL, PU, PL
. a. DMF Score: ___ ___ b. Missing teeth: ___ ___
. OHI-S: (97 = missing; 98 = other; 99 = error)
Tooth #: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ ___
a. Debris Index (0-3): ___ ___ ___ ___ ___ ___
b. Calculus Index (0-3): ___ ___ ___ ___ ___ ___

9. Oral lesions identified?..... Yes 1 No 0

IF NO, STOP HERE. IF YES, COMPLETE THE REMAINDER OF FORM

Photographs taken ..... Yes 1 No 0
If yes, lesi .. #:
1. ___ ___ 2. ___ ___ 3. ___ ___ 4. ___ ___ 5. ___ ___ 6. ___ ___ 7. ___ ___ 8. ___ ___

10. ANGULAR CHEILITIS..... Yes 1 No 0
If yes, location:
a. Right..... Yes 1 No 0
b. Left..... Yes 1 No 0

11. DENTURE STOMATITIS..... Yes 1 No 0

12. PATCHY DEPAPILLATED TONGUE..... Yes 1 No 0
If yes,
a. Smear taken ..... Yes 1 No 0
If yes,
b. Smear result ..... Pos 1 Neg 0

13. MUCOSAL ERYTHEMA ..... Yes 1 No 0

If yes, location:

a. 1-5 areas ..... Yes 1 No 0

IF YES, SPECIFY LOCATIONS

a1) __ __ a2) __ __ a3) __ __ a4) __ __ a5) __ __

b. 6 - 10 areas ..... Yes 1 No 0

c. 11 or more (generalized) ..... Yes 1 No

d. Smear taken ..... Yes 1 No 0

If yes,

e. Smear result ..... Pos 1 Neg 0

14. MUCOSAL PETECHIAE ..... Yes 1 No 0

If yes, location:

a. 1-5 areas ..... Yes 1 No 0

IF YES, SPECIFY LOCATIONS

a1) __ __ a2) __ __ a3) __ __ a4) __ __ a5) __ __

b. 6 - 10 areas ..... Yes 1 No 0

c. 11 or more (generalized) ..... Yes 1 No 0

d. Smear taken ..... Yes 1 No 0

If yes,

e. Smear result ..... Pos 1 Neg 0

15. MEDIAN RHOMBOID GLOSSITIS ..... Yes 1 No 0

If yes,

a. Smear taken ..... Yes 1 No 0

If yes

b. Smear result ..... Pos 1 Neg 0

16. PSEUDOMEMBRANOUS CANDIDIASIS ..... Yes 1 No 0

If yes, location:

a. 1-5 areas ..... Yes 1 No 0

IF YES, SPECIFY LOCATIONS

a1) __ __ a2) __ __ a 3) __ __ a4) __ __ a 5) __ __

b. 6 - 10 areas ..... Yes 1 No 0

c. 11 or more (generalized) ..... Yes 1 No 0

17. CORRUGATED LEUKOPLAKIA (lateral tongue) ..... Yes 1 No 0

If yes, location:

a. Left ..... Yes 1 No 0

b. Right ..... Yes 1 No 0

c. Smear taken ..... Yes 1 No 0

18. NON-CORRUGATED LEUKOPLAKIA (lat'l tongue)..... Yes 1 No 0

If yes, location:

a. Left ..... Yes 1 No 0

b. Right ..... Yes 1 No 0

c. Smear taken ..... Yes 1 No 0

19. LEUKOPLAKIA OTHER (NOT lat'l tongue) ..... Yes 1 No 0

If yes, location:

a. 1-5 areas ..... Yes 1 No 0

IF YES, SPECIFY LOCATIONS

a1) __ __ a2) __ __ a3) __ __ a4) __ __ a5) __ __

b. 6 - 10 areas ..... Yes 1 No 0

c. 11 or more (generalized)..... Yes 1 No 0

20. KAPOSI'S SARCOMA ..... Yes 1 No 0

If yes,

a. Clinical diagnosis ..... Yes 1 No 0

b. Biopsy confirmed ..... Yes 1 No 0

Location:

c. 1-5 areas ..... Yes 1 No 0

IF YES, SPECIFY LOCATIONS

c1) __ __ c2) __ __ c3) __ __ c4) __ __ c5) __ __

d. 6 - 10 areas ..... Yes 1 No 0

e. 11 or more (generalized)..... Yes 1 No 0

21. MINOR APHTHOUS ULCER(S)..... Yes 1 No 0

a. If yes, number: __ __

22. MAJOR APHTHOUS ULCER(S)..... Yes 1 No 0

a. If yes, number: __ __

IF YES, SPECIFY LOCATION(S)

a1) __ __ a2) __ __ a3) __ __ a 4) __ __ a 5) __ __

23. LINEAR MARGINAL ERYTHEMA..... Yes 1 No 0

If yes,

a. Number of surfaces: __ __ (#b & 1 surfaces)

b. Specify locations:

1) __ __ 5) __ __ 9) __ __

2) __ __ 6) __ __ 10) __ __

3) __ __ 7) __ __ 11) __ __

4) __ __ 8) __ __ 12) __ __

c Smear taken ..... Yes 1 No 0

d. Pain at time of examination?..... Yes 1 No 0

e. Sample taken ..... Yes 1 No 0

If yes,

f. Tooth # __ __ Surface: __ __

g. Control # __ __ Surface: __ __

24. NECROTIZING ULCERATIVE GINGIVITIS .. ..Yes 1 No 0

If yes,

a. Number of sites: ___ ___ (#papillae)

b. Specify locations:

1) ___ ___	5) ___ ___	9) ___ ___
2) ___ ___	6) ___ ___	10) ___ ___
3) ___ ___	7) ___ ___	11) ___ ___
4) ___ ___	8) ___ ___	12) ___ ___

c. Smear taken ..... Yes 1 No 0

d. Pain at time of examination?..... Yes 1 No 0

e. Sample taken ..... Yes 1 No 0

If yes,

f. Tooth # ___ ___ Surface: ___ ___

g. Control # ___ ___ Surface: ___ ___

25. NECROTIZING ULCERATIVE PERIODONTITIS .....Yes 1 No 0

If yes,

a. Number of sites: ___ ___ (#papillae)

b. Specify locations:

1) ___ ___	5) ___ ___	9) ___ ___
2) ___ ___	6) ___ ___	10) ___ ___
3) ___ ___	7) ___ ___	11) ___ ___
4) ___ ___	8) ___ ___	12) ___ ___

c. Smear taken ..... Yes 1 No 0

d. Pain at time of examination?..... Yes 1 No 0

e. Sample taken ..... Yes 1 No 0

If yes,

f) Tooth # ___ ___ Surface: ___ ___

g) Control # ___ ___ Surface: ___ ___

26. OTHER HIV ASSOCIATED ORAL LESIONS.....Yes 1 No 0

a.	Exfoliative cheilitis.....	Yes 1	No 0
b.	Herpes zoster	Yes 1	No 0
c.	Focal melanin pigmentation.....	Yes 1	No 0
d.	Herpes labialis.....	Yes 1	No 0
e.	Herpes simplex-like ulcer.....	Yes 1	No 0
f.	Other ulcer.....	Yes 1	No 0
g.	Papilloma.....	Yes 1	No 0

27. OTHER LESIONS..... Yes 1 No 0

Clinical diagnosis: _____

_____

_____

COMMENTS:

_____

_____

Appendix Three: Oral health service utilization questionnaire

DENTAL NEEDS ASSESSMENT

1. Subject ID [ ][ ][ ][ ][ ][ ] 1-6

2. Dental visit# [ ][ ] 7-8

3. Today's date (mo/day/yr) [ ][ ][ ][ ][ ][ ] 9-14

4. Examiner's initials..... [ ][ ] 15-16

5. Date of birth [ ][ ][ ][ ][ ][ ] 17-22

6. How long has it been since your last emergency dental visit? [ ] 23

0 = Never
1 = Less than 6 months
2 = Between 6 months and 1 year
3 = Between 1 and 2 years
4 = Between 2 and 5 years
5 = More than 5 years

7. How long has it been since your last regular scheduled routine dental or dental hygiene visit? [ ] 24

0 = Never
1 = Less than 6 months
2 = Between 6 months and 1 year
3 = Between 1 and 2 years
4 = Between 2 and 5 years
5 = More than 5 years

8. Have you ever had dental pain or infection that went without treatment? ..... [ ] 25

1. Yes 0. No

9. How often do you usually visit the dentist or dental hygienist? ..... [ ] 26

0 = Never
1 = 2 or more times a year
2 = Once a year
3 = Every 2 or years
4 = Only in emergency

10. What was the reason for your last visit to the dentist? ..... [ ] 27

0 = I have never been to the dentist
1 = Something was wrong: I had pain
2 = I though it was time for examination or cleaning
3 = The dentist reminded me it was time for an examination or cleaning
4 = It was part of a serious or course of treatment

5 = Other reason (specify) .....

11. If you don't go to the dentist regularly (at least once a year) why don't you go? [ ][ ][ ][ ] 28-3

0 = I go regularly
1 = I don't have time
2 = I'm afraid of the dentist or the pain involved
3 = It costs too much
4 = I'm afraid I'll contract a disease
5 = I have to travel too far
6 = I have to wait a long time at the dental office
7 = The dentist does not speak my language
8 = I don't think I need to see a dentist
9 = I don't know of any dentist of dental clinic
10 = Dental treatment is not a priority to me

11 = Other reason (specify) .....

12. When you do go to the dentist, where do you go? [ ] 32

0 = I never go to the dentist
1 = Private dentist office
2 = Private dental clinic
3 = Public dental clinic
4 = Hospital dental clinic
5 = Dental school clinic

13. What kind of medical health insurance do you have? [ ] 33

0 = None, I have no health insurance
1 = Medical Aid scheme
2 = Indigent medicate (for those over 65 or disabled)
3 = Private Health insurance
4 = Employer provided, HMO or prepaid plan, employer
5 = Other (specify) .....
6 = Don't know

14. What kind of dental insurance do you have? [ ] 34

0 = None, I have no health insurance
1 = Medical Aid scheme
2 = Indigent medicate (for those over 65 or disabled)
3 = Private Health insurance
4 = Employer provided, HMO or prepaid plan, employer
5 = Other (specify) .....
6 = Don't know

15. How healthy would you say your teeth and mouth are

35

0 = Very healthy, I have no real problems
1 = Okay, but I have some problems
2 = I have pain or discomfort
3 = I feel that I need dental care badly

16. How often do you usually brush your teeth?

36

0 = I don't brush my teeth
1 = A few (2-3) times a month
2 = A few (2-3) time a week
3 = Once a day
4 = Two or more times a day
5 = I don't have any teeth

17. How often do you usually use dental floss to clean your teeth?

37

0 = I don't use dental floss on my teeth
1 = A few (2-3) times a month
2 = A few (2-3) times a week
3 = Once a day
4 = Two or more times a day
5 = I don't have any teeth

18. If you have received dental treatment in the past two years, was it due to your participation in this study?

38

1. Yes 0. No

19. Has participating in this study encourage you to seek dental treatment in the future?

39

1. Yes 0. No

20. Would access to dental educators in your community increase your desire to seek dental treatment?

40

1. Yes 0. No

Appendix Four: Calibration

INTER-RATER CALCAT by CALCATN

CALCAT	Count	CALCATN .00	1.00	2.00	3.00	Row Total
	.00	2				2 10.0
	1.00		7			7 35.0
	2.00			5	1	6 30.0
	3.00				5	5 25.0
	Column Total	2 10.0	7 35.0	5 25.0	6 30.0	20 100.0

Statistic	Value	ASE1	Val/ASE0	Approximate Significance
Kappa	.93031	.06767	6.81165	Excellant
Pearson's R	.97578	.02234	18.92534	.00000 *4
Spearman Correlation	.97742	.02368	19.62574	.00000 *4

*4 VAL/ASE0 is a t-value based on a normal approximation, as is the significance
Number of Missing Observations: 0

INTER-RATER DEBRIS SCORE

DebrisA	Count	Debris B .00	1.00	2.00	3.00	Row Total
	.00	3				3 15.0
	1.00		2			2 10.0
	2.00			5	1	6 30.0
	3.00				9	9 45.0
	Column Total	3 15.0	2 10.0	5 25.0	10 50.0	20 100.0

Statistic	Value	ASE1	Val/ASE0	Approximate Significance
Kappa	.92509	.07356	6.52160	Excellant
Pearson's R	.97984	.01987	20.80863	.00000 *4
Spearman Correlation	.95463	.04527	13.59984	.00000 *4

INTRA-RATER LESION DIAGNOSIS
ORALES by EXAMN

Count	ORALLES2 .00	1.00	Row Total
ORALLES1 .00	6		6 30.0
1.00		14	14 70.0
Column Total	6 30.0	14 70.0	20 100.0

Statistic	Value	ASE1	Val/ASE0	Approximate Significance
Kappa	1.00000	.00000	4.47214	Perfect
Pearson's R	1.00000	.00000		*4
Spearman Correlation	1.00000	.00000		*4

*4 VAL/ASE0 is a t-value based on a normal approximation, as is the significance
Number of Missing Observations: 0

INTER-RATER LESIONS
EXAMA by EXAMB

Count	EXAMB .00	1.00	Row Total
EXAMA .00	5		5 25.0
1.00	1	14	15 75.0
Column Total	6 30.0	14 70.0	20 100.0

Statistic	Value	ASE1	Val/ASE0	Significance
Kappa	.90500	.12088	3.94405	Excellant Agreement
Pearson's R	.91192	.10830	7.93725	.00000 *4
Spearman Correlation	.91192	.10830	7.93725	.00000 *4

Approximate

Inter-rater DMF to test for differences in mean
- - - t-tests for paired samples - - -

Variable	Number of pairs	Corr	2-tail Sig	Mean	SD	SE of Mean
DMF	20	.998	.000	13.2000	6.849	1.531
DMFA				13.2500	6.851	1.532

SIGNIFICANT CORRELATION

Paired Differences Mean	SD	SE of Mean	t-value	df	2-tail Sig
-.0500	.394	.088	-.57	19	.577
95% CI (-.234, .134)					

*4 VAL/ASE0 is a t-value based on a normal approximation, as is the significance
Number of Missing Observations: 0

Appendix 5. EC-Clearinghouse Guidelines

AN UPDATE OF THE CLASSIFICATION AND DIAGNOSTIC CRITERIA OF ORAL LESIONS IN HIV INFECTION

*EC-Clearinghouse on Oral Problems Related to HIV Infection and WHO Collaborating Centre on Oral Manifestations of the Immunodeficiency Virus**

CALIBRATION AND COHORT STUDIES

LONDON 17th-18th September 1992

Clearinghouse Co-ordinator: J.J. Pindborg
Working Group Chairman: D.M. Williams
Rapporteur: M.H. Thornhill

*The group consisted of T. Axéll, A.M. Azul, S. Challacombe, G. Ficarra, S. Flint, D. Greenspan, J.S. Greenspan, C. Hammerle, G. Laskaris, I. Loeb, M. Lucas-Tomas, R.A. Monteil, J.J. Pindborg, P. Reichart, P. Robinson, C. Scully, P. Swango, S. Syrjänen, M.H. Thornhill, I. van der Waal, D.M. Williams and D. Wray.

The working group met under the chairmanship of D.M. Williams to review the diagnostic criteria for oral lesions seen in HIV infection. Discussion was based on the report of the previous working group meeting, held in Amsterdam in 1990 (J. Oral Pathol. Med. 1991; 20: 97-100). The most significant revisions were the inclusion of presumptive and definitive criteria for the conditions listed; removal of reference to HIV in the names of conditions listed; and classification of the problem of periodontal disease in this group of patients.

This revised classification attempts to reconcile differences between the EC-Clearinghouse group's first proposals and the approach adopted by the US working group (Oral Surg. Oral Med. Oral Pathol. 1992; **73**: 142-4).

The group also gave consideration to the establishment of a network for collaborative research on oral aspects of HIV infection. D.M. Williams accepted responsibility for the co-ordination of this exercise.

DIAGNOSTIC CRITERIA OF ORAL LESIONS

In general these criteria assume a working knowledge of oral mucosal disease. They have been divided into presumptive and definitive criteria. The former are largely for clinical and epidemiological use and are those which will be applied on the first clinical encounter with the patient. It is accepted that they may not be perfect, because other diseases may present with similar appearances. The definitive criteria are those necessary to establish an absolute diagnosis and may require further clinical or laboratory tests. In view of the possibly serious implications of the diagnoses listed in Group 1, the definitive as well as the presumptive criteria should be fulfilled before the diagnosis is accepted in patients not known to be HIV positive.

Further refinement of the diagnostic criteria described here will depend on properly conducted studies to validate them.

Group 1. Lesions strongly associated with HIV infection

Candidiasis

The group reviewed the previous classification of the EC clearing house and made revisions. Specifically, hyperplastic candidiasis has been removed from the classification.

Erythematous Candidiasis

Presumptive criteria

Red area usually located on the palate and dorsum of the tongue, but occasionally on the buccal mucosa. White spots and plaques may be seen but these are not usually conspicuous.

Definitive criteria

At present there are no definitive criteria for this entity. However, the detection of Candida albicans and / or the response to anti-fungal therapy may help to establish the diagnosis.

Pseudomembranous Candidiasis

Presumptive criteria

White or yellow spots or plaques which may be located in any part of the oral cavity and can be wiped off to reveal an erythematous surface which may bleed.

Definitive criteria

1. The principal defining criterion is the response of lesions to anti-fungal therapy.

2. Tests for the presence of Candida albicans are not essential for diagnosis, although they may enhance it, particularly in cases resistant to anti-fungal therapy. These tests may include smears or culture.

Notes:

1. Angular cheilitis can be associated with Candida albicans, and may be seen in dentate patients with HIV infection.

2. Denture induced stomatitis due to Candida albicans may also be seen in patients with HIV infection.

3. Different types of candidiasis may coexist in the same patient.

Hairy leukoplakia

Presumptive criteria

Bilateral whitish/grey lesions on the lateral margins of the tongue. They are not removable and may exhibit vertical corrugations. Lesions may extend onto the ventral and dorsal surfaces of the tongue, where they are usually flat. In addition, lesions may rarely occur on the buccal mucosa.

Definitive criteria

1. Demonstration of EBV in the lesions.

2. In the absence of facilities to demonstrate the presence of EBV, a lack of response to anti-fungal treatment or the demonstration of an immunedeficient status will add weight to the presumptive diagnosis.

Note:

Histological features resembling those seen in hairy leukoplakia may be seen in the absence of EBV infection. For this reason the histological changes are insufficiently specific to be acceptable as definitive criteria.

Periodontal disease

In addition to the specific forms of periodontal disease described below it should be appreciated that chronic marginal gingivitis and adult periodontitis can occur in patients with HIV infection. The clinical appearances of these conditions may, however, be altered or exaggerated as a result of immunosuppression.

In reviewing the previous classification of HIV-related periodontal disease the EC clearing house have made a number of significant changes. Specifically, HIV-gingivitis has been renamed *Linear gingival erythema*, HIV-necrotising gingivitis has been renamed *Necrotising (ulcerative) gingivitis* (NUG) and HIV-periodontitis has been renamed *Necrotising (ulcerative) periodontits* (NUP). In addition, the criteria defining these conditions has been changed.

Linear gingival erythema

Presumptive criteria

A distinct fiery red band along the margin of the gingiva. The amount of erythema is disproportionately intense for the amount of plaque seen. No ulceration is present and there is no evidence of pocketing or attachment loss.

Definitive criteria

This is at present a clinical diagnosis without definitive criteria. However, a feature of the lesion is that it does not respond well to oral hygiene measures, and the removal of dental plaque and calculus.

Notes:

The microbiology of this lesion has not been defined and whether candidal species are involved in the aetiology remains to be established.

Necrotising (ulcerative) gingivitis

Presumptive criteria

Destruction of one or more interdental papillae. In the acute stage of the process ulceration, necrosis and sloughing may be seen, with ready haemorrhage and characteristic foetor.

Definitive criteria

This is a clinical diagnosis without definitive criteria.

Necrotising (ulcerative) periodontitis

Presumptive criteria

Periodontitis characterised by soft tissue loss as a result of ulceration or necrosis. Exposure, destruction or sequestration of bone may be seen, and the teeth may become loosened. Pain may be a prominent feature.

Definitive criteria

This is a clinical diagnosis without definitive criteria.

Notes:

1. Tissue destruction may extend across the muco-gingival junction.

2. This is a chronic disease which may be seen with ulceration during an active phase or without ulceration during a less-active phase.

3. There is usually rapid loss of attachment, but pocketing may be minimal due to the concurrent loss of hard and soft tissues.

Kaposi's sarcoma

Presumptive criteria

One or more erythematous, slightly bluish or violaceous macules or swellings with or without ulceration. Predominantly seen on the palate or gingiva.

Definitive criteria

Characteristic histological appearance on biopsy.

Non-Hodgkin's lymphoma

Presumptive criteria

A firm elastic, often somewhat reddish or purplish swelling, with or without ulceration. The gingiva, palatal mucosa and fauces are sites of predilection.

Definitive criteria

Characteristic histological appearance on biopsy, supported by appropriate immunocytochemical or molecular biological investigations.

CHANGES TO THE CLASSIFICATION OF GROUP 2 AND 3 LESIONS

***Group 2.* Lesions less commonly associated with HIV infection**

Among the changes made to this part of the classification, cytomegalovirus infections have been moved from Group 2 to Group 3 while melanotic pigmentation has been transferred from Group 3 to Group 2. Bacterial infections caused by *Mycobacterium avium-intracellulare* or *Mycobacterium tuberculosis* have also been transferred from Group 3 to Group 2. Necrotising (ulcerative) stomatitis has been added to the Group 2 list and its criteria are decribed below. Atypical ulceration is removed from the list and replaced with the term Ulceration NOS (not otherwise specified) whose criteria are described below

Necrotising (ulcerative) stomatitis

Presumptive criteria

Localised acute, painful ulceronecrotic lesion of the oral mucosa that exposes underlying bone or penetrates or extends into contiguous tissues. These lesions may extend from areas of necrotising periodontitis.

Definitive criteria

Histological features are those of non-specific ulceration. Microbiological studies fail to identify a specific aetiological agent.

Ulceration NOS (not otherwise specified)

Presumptive criteria

Ulceration with a predeliction for the pharynx and palate which does not correspond to any of the recognised patterns of recurrent aphthous stomatitis (RAS).

Definitive criteria

Histological features are those of non-specific ulceration. Viral or bacterial cultures fail to identify a specific aetiological agent.

Group 3. **Lesions seen in HIV infection**

This group was previously entitled "Lesions possibly associated with HIV". Several conditions in this group have been removed from the classification completely. They include: Bacterial infections caused by *Enterobacter cloacae*, exacerbation of apical periodontitis, osteomyelitis, sinusitis, submandibular cellulitis and, perhaps most notably, squamous cell carcinoma. Melanotic hyperpigmentation has been transferred from Group3 to Group 2. A new section for viral lesions has been introduced into Group 3 to include cytomegalovirus-associated lesions (moved from Group 2) and molluscum contagiosum.

Finally, recurrent aphthous stomatitis (RAS) has been added to Group 3. Although the overall incidence of RAS may not be greater in HIV positive individuals, the incidence of the major or herpetiform type of RAS is increased.

ACKNOWLEDGMENTS

Additional financial support for this meeting from Unilever Dental Research is gratefully acknowledged.

Appendix 6. Qualitative study questionnaire

Staff Perceptions on the delivery of HIV Services Questionnaire

1. ID.....

2. Occupation .....

3. Site .....

Staff perceptions

4. Should care for HIV+ persons services be provided at dedicated clinics or comprehensive clinics. Why?

.....
.....
.....
.....

5. Which level of HIV care should the following persons provide care.
   Oral Hygienists
   Dentists
   Specialists/Consultants

6. Why.....

7. Do you think the community/ primary level clinics are adequately resourced to treat HIV infected patients

.....

8. Why.....

9. If not, what are the limitations

.....
.....
.....
.....

10. How can one overcome these limitations

.....
.....

11. What role should tertiary clinics play in the overall care of the HIV patient.....
.....
.....
.....

12. What role should academic institutions play in the overall care of the HIV patient.....
.....

13. Have you ever treated an HIV infected person

.....
.....
.....

14. If No, how would you feel when treating this person?

.....

15. Why?.....

16. If yes, How did you feel when treating this patient?

.....
.....
.....
.....

17. Why?.....

18. Have you ever had a needle stick injury

.....
.....
.....
.....

19. If yes what precautions did you follow.

.....
.....
.....
.....

20. If Not, why

.....
.....
.....
.....

21. Are you aware of any protocols for the management of this injury?

.....
.....
.....

Appendix 7. Cost Estimates

Treatment was provided on the basis of Guidelines developed by Arendorf et al. (1997). Guidelines for the diagnosis and the management of oral manifestations of HIV and AIDS, Faculty of Dentistry, Univ of Western Cape (ISBN 1-806808-306-3).

Drugs were priced at State tender prices for 1996-8

Items		Rands 1996/1997-1998
Nystastin ointment	15 ml tube@	R8.87 –R9.57
Amphothericin- B Lozenges	20 tablets@	R23.51- R25.86
Chlorhexidine Mouthrinse (0.2%) I bottle @		R3.91- R4.30
Miconazole Gel	1 tube @	R32.62- R35.88
Flagyl 400mg tablets	1 tablet @	R0.10- R 0.11
Orabase Ointment	1 tube @ for 5g	R 7.75- R 8.52
	for 30g	R 20,97-R23.06
Kenalog in Orabase	for 5g	R14,53- R15.98
Dispensing fee per item for Scheduled drugs		R1,43(Fixed)

Laboratory Tests at Regulated Medical Rates 1996/7-1998

Items	1996/7-1998 Rands
Kaposi's sarcoma biopsy standard block @	R84.00 - R94.00
Per additional specimen if large @	R10.50-R11.80
Candida albicans Microscopy @	R15.70-17.60
Candida albicans Culture @	R23.60
CMV histology @	R250
Biopsy Procedure @	R100.40
Smear Procedure @ 8787X 2/3 of R66.70	R44.46

Procedure, Code and Cost in Rands

Procedure and Code		Rands		
		1996	1997	1998
Examination	8104	R18.94	R20.65	R25.90
Oral Hygiene Instruction	8151	R28.78	R31.77	R39.30
Infection control per operator	8109	R 3.77	R 4.11	R5.10
Total [6]		**R51.49**	**R56.53**	**R70.30**

[6]The cost of care does vary from site to site. For example, a study examining cost of preventive dental care in the state sector revealed that the cost ranged from R28 to R63. Khalfe AD. (1995).A comparative analysis of delivering different modes of dental care at district level. Thesis M.CHD. Community Dentistry (UWC).

Appendix 8. Photographs of Oral HIV lesions

PHOTOGRAPHS OF ORAL HIV-RELATED LESION

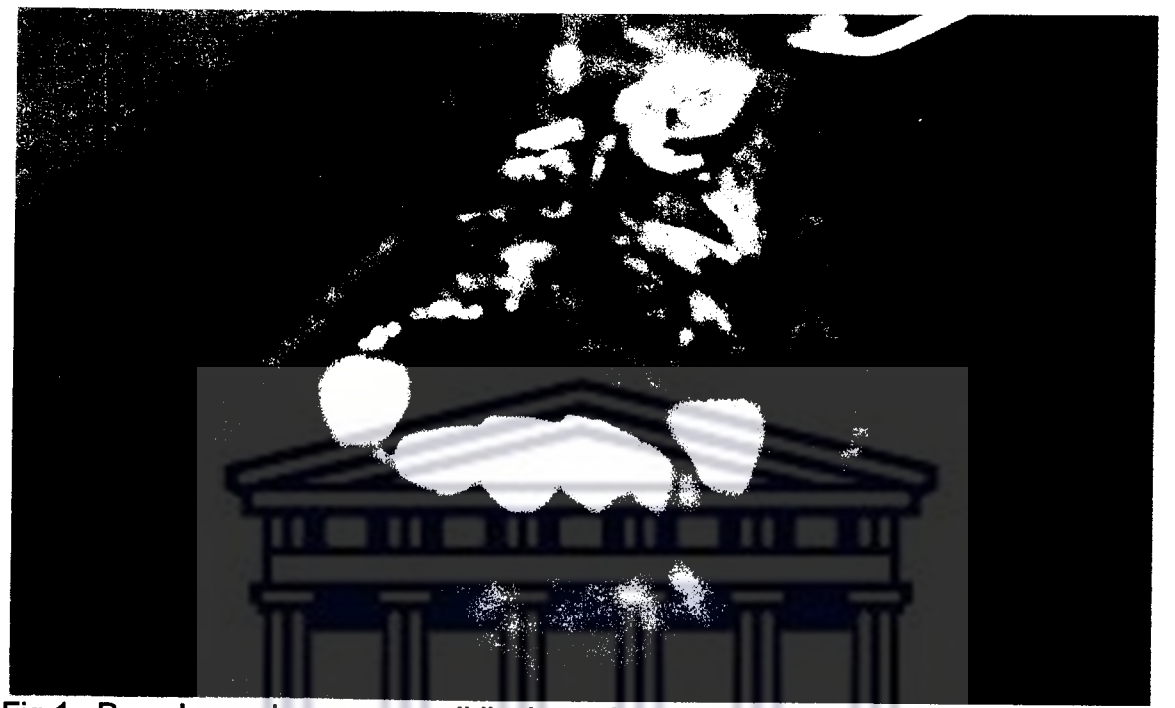

Fig 1. Pseudomembranous candidiasis on the upper anterior alveolar ridge and labial area

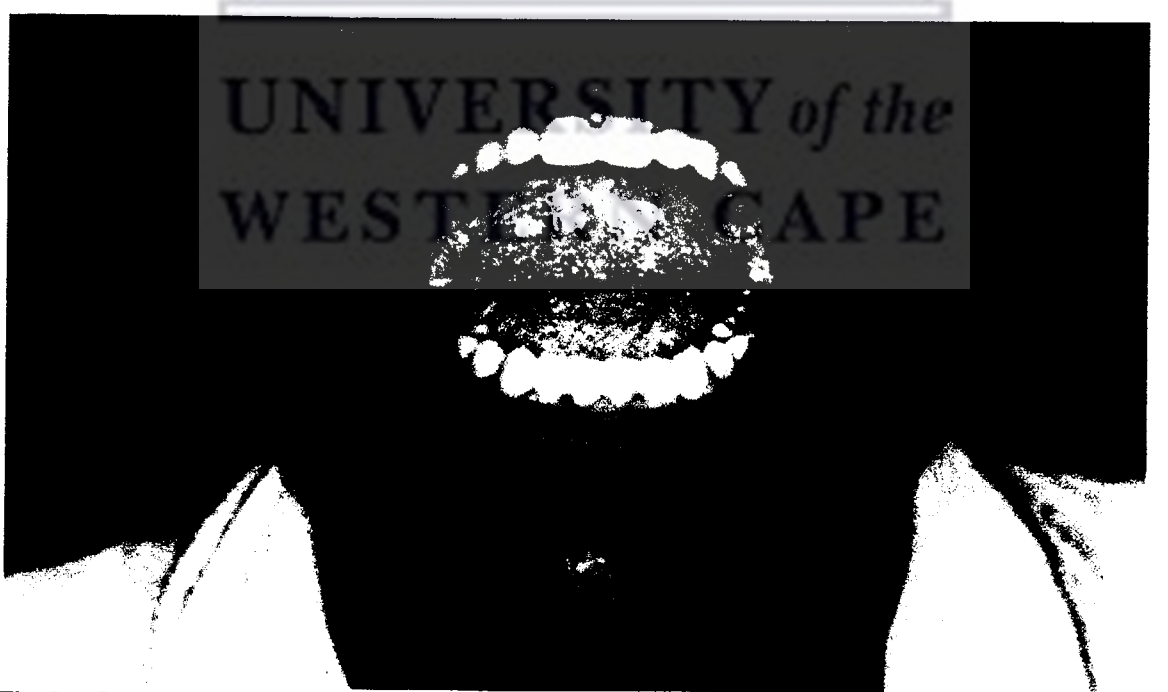

Fig 2. Generalised Pseudomembranous Oral Candidiasis in a patient with AIDS

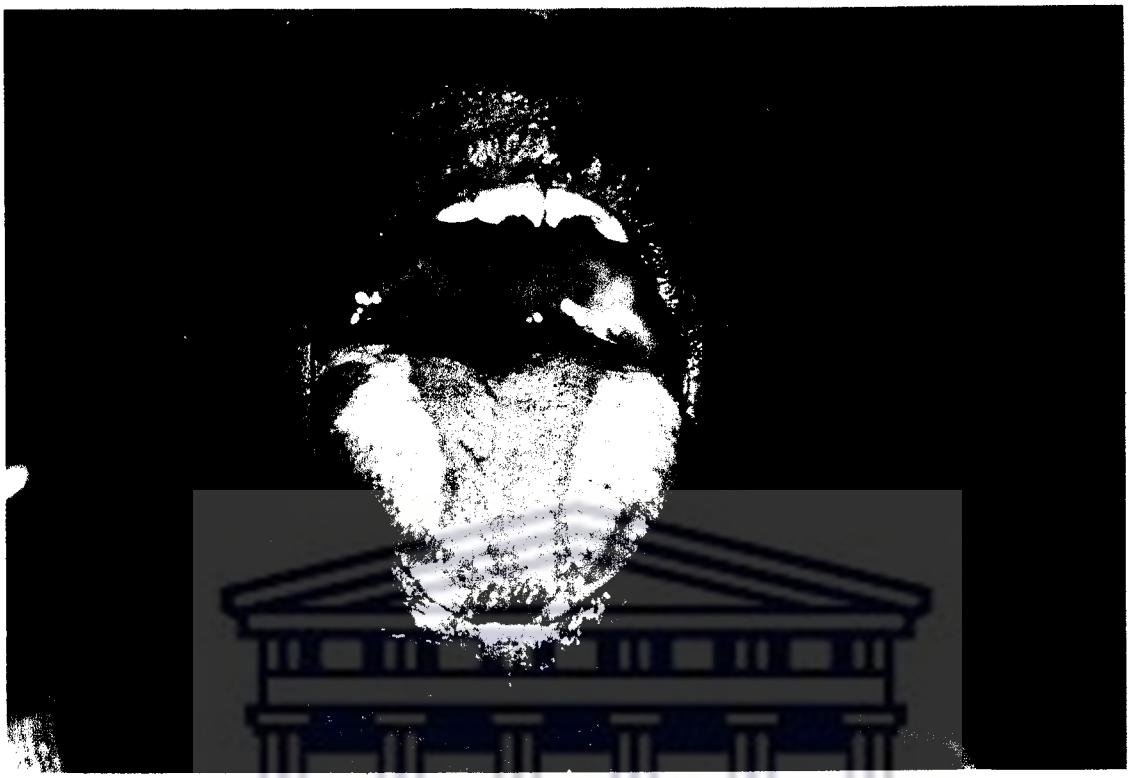

Fig 3. Erythematous Candidiasis on the tongue with a "matching" lesion on the palate

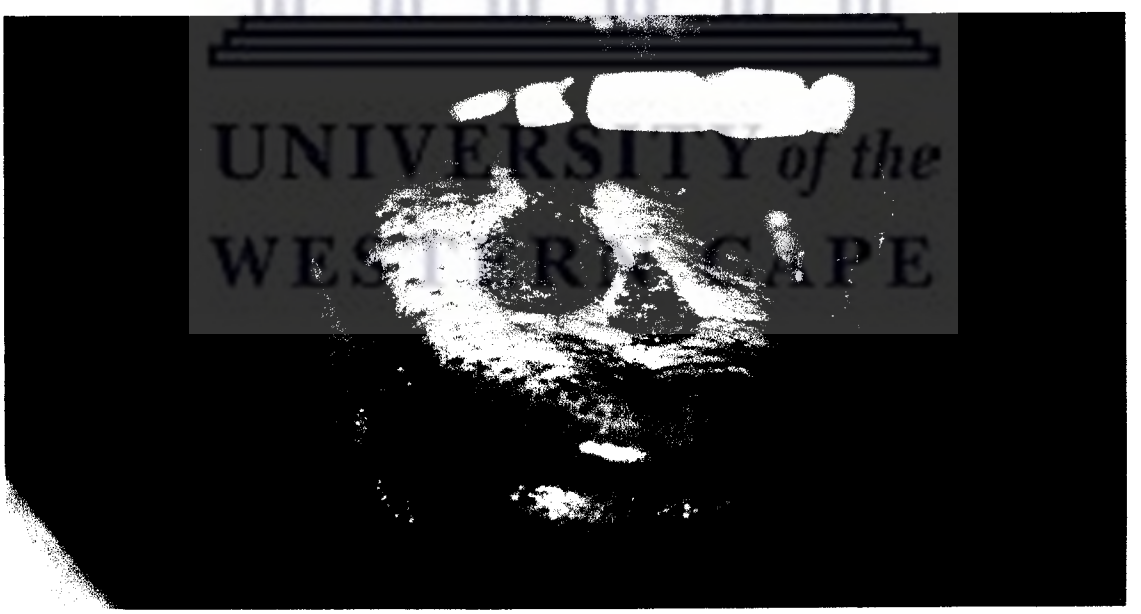

Fig 4. Erythematous Candidiasis

Fig 5. Acute (ulcerative) Gingivitis on lower anterior area

Fig 6. Acute (ulcerative) periodontitis on lower anterior incisal area, pseudomembranous candida on upper labial region

Fig 7. Oral Hairy Leukoplakia on the lateral border of tongue.

Fig 8. Oral "Non Hairy" (non-corrugated) Leukoplakia on lateral and ventral surface of tongue.

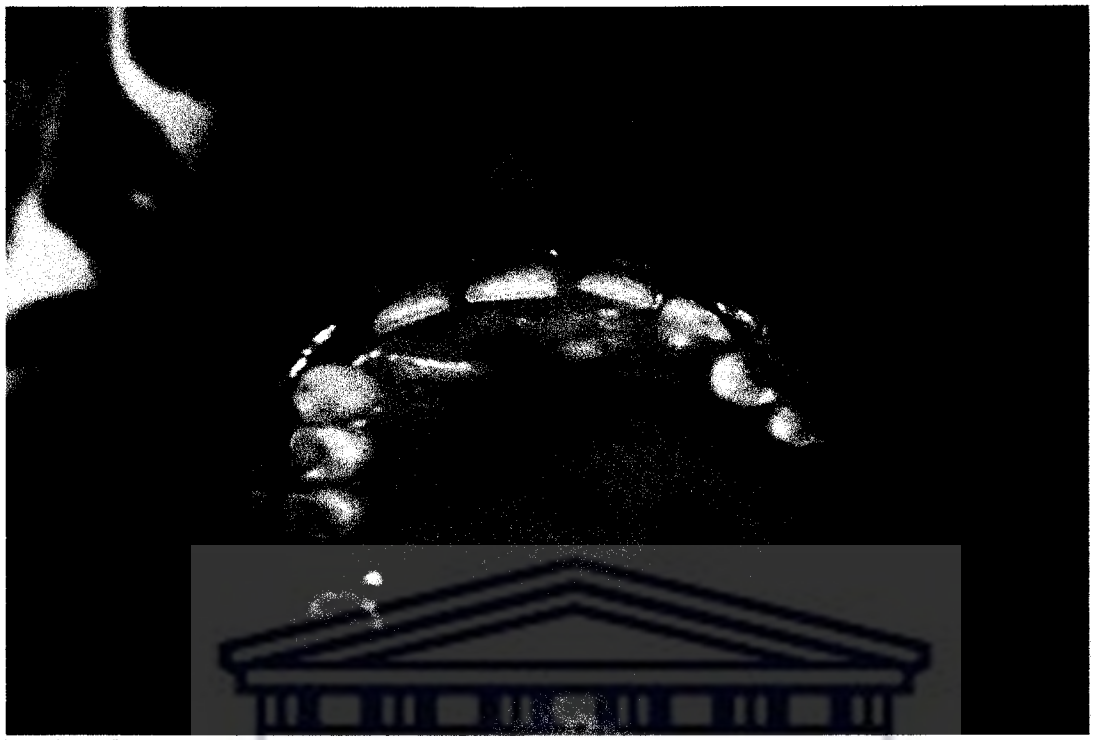

Fig 9. Macular Kaposi's Sarcoma on the palate

Fig 10. Herpes Simplex Ulcer on lower lip and smooth atrophied fissured tongue