

Knowledge, Attitudes and Practices of caregivers about oral lesions in HIV positive patients in NGOs /CBOs in Region 8, Johannesburg, Gauteng

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Declaration

I, Yolanda Malele-Kolisa (Student No. 8803104E), hereby declare that this report is my own work. It is being submitted for the degree of Master of Dentistry: Community Dentistry at the University of the Witwatersrand, Johannesburg. It has not been submitted or presented for any degree or examination at this or any other university.

Signed at Johannesburg on theë .ë ..day of February in the year 2009.

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Dedication

For my lovely girls, Kearabetswe, Kgothatso and Bontle

In loving memory of my late mother Nobantu, for her ambition, humility, determination and earnest dedication to life; *Wa hae mosebetsi o o phethile.*

*'Seek **his** will in all you do, and **he** will direct your paths.'* (New Living Translation; Proverbs 3:6)

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Abstract

Title: Knowledge, Attitudes and Practices of caregivers about oral lesions in HIV positive patients in NGOs /CBOs in Region 8, Johannesburg, Gauteng.

Background: The HIV pandemic continues to be a major public health problem in South Africa where 11% of people were infected with HIV in 2005(HSRC, 2005).The care and support of these patients as they eventually become ill will necessitate the increase in use of community-based/home-based/hospice institutions. The City of Johannesburg (CoJ), one of the metropolitan municipalities (local government) in Gauteng Province-SA, has been planning the development and implementation of programmes related to the prevention, care and support for people infected and affected by HIV/AIDS. Care and support has been limited to 18 NGOs/ CBOs. Four of these institutions provide palliative care and are staffed by 64 caregivers. Studies done throughout the world indicate that oral lesions associated with HIV occur in over half of HIV/AIDS patients. These oral lesions seriously impair the oral-health-related-quality of life in affected individuals and necessitate the need to provide services to alleviate them and improve patient comfort. The caregivers in the NGOs/CBOs are therefore pivotal in offering care and support in the management of HIV including the management of oral lesions. In order for the caregivers in the NGOs/CBOs to be able to manage the disease in its entirety; they need optimal knowledge of the infection/illness including the oral manifestations associated with the ailment.

Objectives: (1.) To determine the knowledge of the caregivers in the NGOs/CBOs providing palliative care in Region 8, CoJ, Gauteng regarding common oral manifestations associated with HIV. of the caregivers in the NGOs/CBOs . (2.) To assess the attitudes of the caregivers in the NGOs/CBOs providing palliative care in Region 8, CoJ, Gauteng on common oral manifestations associated with HIV. (3.) To determine the practices of the caregivers in the NGOs/CBOs in Region 8, CoJ, Gauteng, pertaining to the common oral manifestations associated with HIV. (4.) To determine the socio-demographic profile of the caregivers providing palliative care in the NGOs/CBOs in Region 8, CoJ, Gauteng.

Methods: A descriptive cross-sectional study was conducted where all caregivers providing care and support in the four NGOs/CBOs were invited to participate in the study. Data was collected by a customised questionnaire to obtain information on demographics, knowledge, attitudes and practices on providing for HIV positive patients.

Results: The results were grouped according to training in oral health care (TOHC) and no training (NTOHC). The mean age was 43.5 years for TOHC and 30.8 years NTOHC and was statistically significant ($p<0.005$). There were statistical significant differences in the gender proportions in within groups in the both groups, employment status, work experience as a caregiver and training in general home-based care ($p<0.05$). Most (72.2%) of those NTOHC had little experience (<1 year) of care giving compared to 41.1% ($p=0.03$) and 33.3% were providing care without training in home-based care (HBC) compared to 100% ($p=0.00$). The caregivers trained in oral health care had knowledge levels shown by higher knowledge levels on four of seven variables compared to those who were not trained in oral health care ($p<0.05$, Table 3.3 p.21). The majority of caregivers NTOHC reported that caring for the mouth of HIV positive patients is an unpleasant difficult task and poses an infection risk to the caregivers while these concerns were expressed by the minority of caregivers TOHC ($p<0.05$). Practices performed by caregivers NTOHC were appropriate for **dry mouth, difficulty in swallowing** but was inappropriate for bleeding gums and bad breath while those caregivers TOHC provided appropriate advice/practices for **oral thrush, bad breath, bleeding gums, dry mouth** with statistical difference.

Conclusion: The caregivers TOHC had fairly better knowledge, attitudes and practices regarding oral lesions in HIV compared to those NTOHC. There was strong likelihood of knowledge variables and training in oral health care.

Recommendations: Bearing in mind the limitations of KAP surveys and the cross sectional nature of the study, it is recommended that training in oral health care and refresher courses for those trained must be incorporated into the programme of all caregivers working in palliative institutions because it will provide specialised knowledge about oral health and oral lesions in HIV improve their knowledge, attitudes and practices and thus provide a better service to their patients.

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List of Abbreviations

AIDS- Acquired Immune Deficiency Syndrome

CBO-Community-based Organisation

CoJ- City of Johannesburg

DoH- Department of Health

EC ñ European Clearinghouse

ECC ñ European Clearinghouse Classification

Etc.- etcetera

GDoH-Gauteng Department of Health

HIV- Human Immunodeficiency Virus

HL - Hairy Leukoplakia

HSRC- Human Science Research Council

KAP ñ Knowledge, Attitudes and Practices

LGE ñ Linear Gingival Erythema

NGO- Non-Governmental Organisation

NTOHC- Not trained in Oral Health Care

NUG - Necrotising Ulcerative Gingivitis

OHCE - Oral Health Care Education

OR-Odds Ratio

OT- Oral Thrush

PLWA- People living with AIDS

SA- South Africa

Std dev- Standard Deviation

TOHC- Trained in Oral Health Care

UK-United Kingdom

WHO- World Health Organization

Chapter 1: Introduction and Background

1.1 Introduction

The HIV pandemic continues to be a major public health problem in South Africa (SA) where 10.8% (4.8million) of persons aged 2 years and older are infected with HIV in 2005 (Human Science Research Council (HSRC), 2005). The care and support of these patients as they eventually become ill will necessitate the increase in use of community-based/home-based/hospice institutions.

With the current incidence and prevalence rates of HIV infection (HSRC, 2005), it is thus imperative that management of HIV/AIDS be a priority. In order for the effective management of HIV including oral manifestations of the disease to be fully realized, knowledge and practices regarding oral manifestations of HIV by all professional and lay people involved in the care and support of patient is essential.

Studies done throughout the world indicate that oral lesions associated with HIV occur in over half of HIV/AIDS patients (Lim et al., 2002; Arendorf et al., 1998; Ramirez-Amador, et al., 1998). These oral lesions can have physical, economic, social and psychological consequences for the patient and seriously impair the oral-health-related-quality of life in affected individuals (Yengopal, 2003; Bajomo, 2004; Gift & Redford, 1992).

In a study done in a hospice in Soweto, mouth pain was reported as the second most prevalent symptom as reported by 50.5% of AIDS patients (Norval, 2004). In another study done at a research site situated in a Soweto hospital, the prevalence of mouth pain and/ or discomfort as reported by HIV positive patients was 57% (Malele et al., 2007).

There is therefore a need to provide services to alleviate oral problems and improve patient comfort. The caregivers in the NGOs/CBOs are pivotal in offering care and support in the management of HIV including the management of oral lesions. In order for the caregivers in the HIV/AIDS NGOs/CBOs to be able to manage the disease in its entirety, they need optimal knowledge of the disease including the oral manifestations associated with the illness.

1.2 Background

The HIV/AIDS Strategic Plan for South Africa 2000-2005 has two primary goals (Department of Health (DoH), 2000): Firstly, to reduce the number of new HIV infections and secondly, to reduce the impact of HIV/AIDS on individuals, families and communities. The Strategic Plan emphasizes several strategies one of which is to improve care and treatment of people living with HIV/AIDS and to promote a better quality of life (Centre for Health Systems Research & Development, 2002). There are three programmes, which are linked by referral systems: community support, health care services and palliative care. The palliative care programme relies immensely on the caregivers in the NGOs/CBOs.

The Gauteng AIDS Programme, which is part of the HIV/AIDS Strategic Plan for South Africa 2000-2005, defines its palliative care programme as providing care in conjunction with curative treatment to improve patient comfort and quality of life. The programme covers home-based care services and hospice beds run by NGOs/CBOs funded by the Gauteng Department of Health (GDoH) (Gauteng AIDS Programme Annual Report 2004/05).

The City of Johannesburg (CoJ) is the largest metropolitan municipality (local government) in Gauteng Province, South Africa. Since 2001, the city has been planning the development and implementation of programmes related to the prevention, care and support for people infected and affected by HIV/AIDS (City of Johannesburg HIV/AIDS Programme (2004). Care and support has been limited to 18 NGOs/CBOs situated in Region 8, an inner city precinct and one of the 11 demarcated regions. These NGOs/CBOs are involved in the following care and support programmes: Hospice/Palliative Care; Home Based Care; Outreach HIV/AIDS Care; People Living with AIDS (PLWA) Project; Awareness Campaigns and Local Area HIV/AIDS Care (Dlamini & Rudolph, 2004).

Community caregivers employed in these NGOs/CBOs are trained in home care and counseling according to national guidelines. They assist families by providing care in the homes of HIV/AIDS patients who are terminally ill, and play a pivotal role in the management of this disease (Dlamini & Rudolph, 2004). Their knowledge and practices regarding oral health and oral diseases related to HIV is essential so that they can provide a general as well as oral health care package to patients.

1.3 Literature review

1.3.1 Knowledge, Attitudes and Practices (KAP) of health caregivers

A Knowledge, Attitudes and Practices (KAP) survey is a needs assessment study which intends to determine the knowledge, (K) attitudes (A) and practices (P) of a population or community. It is based on a questionnaire used in a representative sample of the population being studied. In certain instances KAP surveys may also be used in the evaluation of a programme. In those instances, surveys should be conducted before and after the intervention in order to distinguish effects of the intervention (Mynors-Wallis & Davis, 2004; Andrien, 1994). KAP surveys can be used to provide policy guidelines in addition to providing the overall scenario on the issue in which they are designed. The main purpose of this KAP study is to explore the knowledge levels, attitudes and practices of caregivers working in palliative care institutions on the oral manifestations of HIV.

The knowledge for this study population refers to their understanding of the oral manifestations of HIV. The attitudes are their feelings and pre-conceived ideas towards oral manifestations. The practice refers to the ways in which they demonstrated their knowledge and attitudes through their actions.

KAP surveys are often used to identify gaps in knowledge and attitudes. This KAP study gathered information about what respondents know about oral manifestations of HIV, what they thought about them and what they actually did for the patients who presented with oral manifestations of HIV. KAP surveys can identify information and factors influencing behaviour. For instance, in Nigeria, a study was designed to test health care workers (doctors, nurses) knowledge about HIV transmission and their attitude towards people living with HIV and AIDS. Though many of the respondents demonstrated good knowledge about HIV transmission, more than 25% of them thought that HIV could be transmitted through saliva, vomit, faeces and urine. They over estimated their risk of acquiring HIV infection following needle stick injury, exposure of mucocutaneous membrane and intact skin to infected blood and body fluids. Over 40% of the health care workers exhibited discriminatory attitude towards people living with HIV and AIDS (Aisien et al., 2005).

KAP surveys are also useful to measure the impact of health interventions and education programs. An American study conducted in 2005 assessed the dental hygienists infection control practices and their attitudes and practices toward patients with infectious diseases documented. The majority of dental hygienists reported altering infection control practices and treatment techniques when treating HIV/AIDS or hepatitis patients. While there was an improvement in compliance with recommended infection control guidelines, practitioners still had misconceptions, and were worried about infectious diseases and disease transmission (King & Muzzin, 2005).

The limitations of KAP surveys have been documented in the literature Smith (1993). The validity of data collected using quantitative KAP survey interviews to understand people's knowledge and attitudes has been questioned, particularly when investigating sensitive topics such as HIV/AIDS (Smith, 1993).

Furthermore, the context in which KAP surveys are undertaken must be considered. For example, cross-cultural nuances may affect the results, but are often difficult to evaluate in KAP surveys. People might also feel uncomfortable revealing information about themselves or others in their lives. This highlights the fact we often rely solely on KAP survey data to understand complex issues. Triangulation of methods is recommended to enable collection of meaningful data .

Another limitation with KAP surveys is that if variables are pre-coded, this almost leads to the participants towards the responses listed, and might not be an accurate reflection of real knowledge or attitude levels in the group studied.

1.3.1.1 Definition of terms

Oral lesions in HIV positive patients refer to oral conditions experienced by HIV/AIDS patients because of the compromised immune response as a result of their HIV status. These lesions are classified according to the European Clearinghouse Classification (ECC) and WHO (EC-Clearinghouse, 1993)

Note: For the purposes of this study the definition of the lesions were described in layman's terms in the questionnaire (Annexure II).

Caregiver: : For the purposes of this study a caregivers is a person from a community (ancillary or auxiliary) who is trained to provide comprehensive health care and support for people infected and affected by HIV/AIDS in the NGOs /CBOs, which may include nurses.

1.3.2 KAP amongst non-dental and dental health care workers regarding HIV/AIDS

There are several KAP studies which have been undertaken on different categories of health workers to assess their general knowledge of HIV/AIDS, their attitudes and their practices in treating infected patients.

Several studies reviewed below, from both developed and developing countries, demonstrated that health workers seem to have little or poor knowledge on HIV, continue to have negative attitudes towards HIV with regards risk of infection, discriminate against HIV infected patients and have low willingness to care for infected patients.

In a KAP survey done to analyse the social construction of discrimination processes associated with HIV/AIDS based on the perceptions of health care providers in three states of the Mexican Republic; 75% of these providers reported having received training related to HIV/AIDS. However, notions of discrimination persisted due to the issues of risk; having the syndrome and death (Infante et al., 2006).

In Italy, a KAP survey was undertaken to analyse knowledge, perception of risk, attitudes and behaviour towards HIV infection among health workers in two hospitals in the north-east of Italy. There was a high perception of the risk of acquiring HIV infection through occupational exposure. Scientific knowledge about transmissibility of HIV infection was poor. A significant portion of health workers showed low willingness to care for HIV-positive patients and negative behavioural attitudes persisted (Brusafero et al., 1997)

Health care workers (physicians, midwives, nurses, medical students and nursing auxiliaries) were surveyed in HIV/AIDS-related knowledge, attitudes and practices in Tamatave (Madagascar) in order to assess the feasibility of voluntary counseling and testing for HIV infection in antenatal care. The results show that scientific knowledge about transmissibility of HIV infection was poor.

Almost 80% believed that they were at risk of acquiring AIDS, mainly through occupational exposure. Negative attitudes towards HIV-positive patients were also noted with 20% of the health workers mentioning that AIDS patients should be isolated in quarantine. Physicians and paramedical staff differed only in their better knowledge about transmissibility of HIV. Physicians had the same restrictive attitude towards patients with HIV as paramedical health workers and did not differ in their counseling practice (Hentgen et al., 2002).

Another study in Nigeria was performed on health (doctors and nurses) and non-health care workers to assess their knowledge of AIDS (for both groups) and the attitude of the health workers towards the care of patients with AIDS. Although important gaps in knowledge were found in all groups, doctors not unexpectedly performed significantly better than non-health workers and nurses on knowledge items and nurses in turn scored significantly higher than non-health workers. About a third of nurses and about a quarter of doctors expressed their hesitation to nurse a patient with HIV/AIDS (Adelekan et al., 1995).

1.3.3 KAP amongst dental health workers regarding HIV/ AIDS

When KAP studies specific to oral health workers were assessed, the review of studies below highlight similar knowledge gaps and negative attitudes and perceptions were found when compared to other health categories of workers.

A survey was conducted among dental practitioners in Ireland to determine their knowledge, attitudes and the concerns towards HIV infection. The majority of dentists had sufficient knowledge regarding the etiology of AIDS and the oral manifestations associated with HIV, but there were considerable gaps regarding dental management. Only 41% were prepared to provide continued care of HIV infected patients while contradicting opinions were expressed on the risk of HIV transmission in dentistry and attitudes towards HIV positive patients and staff (McCartan and Samaranayake, 1991).

In Japan, a study was undertaken to investigate knowledge of AIDS and HIV infection among Japanese dental health care workers as well as the source of that knowledge and attitudes of dental workers towards infected patients. Almost all considered their knowledge of AIDS and HIV infection to be more than satisfactory but nevertheless still inadequate. The majority of respondents would be hesitant about performing dental treatment on HIV-positive patients. Many were anxious about the increasing occupational risk of HIV infection.

However, most also considered that they would be able to take care of the oral opportunistic diseases associated with HIV. Over 90% of respondents requested additional education about HIV, particularly information about the prevention and spread of the virus and cross-infection requirements (Kiatura et al., 1997).

A survey was performed in Kenya, the purpose of which was to assess dentists' knowledge of HIV/AIDS, attitudes pertaining to universal precautions and treatment of patients with HIV/AIDS and their behaviour toward their patients. More than half the sample (53%) knew that the first AIDS patient in Kenya was reported in 1984. Most (68%) dentists indicated a willingness to treat HIV/AIDS patients while those with dissenting views preferred that they be treated in dedicated clinics or academic teaching hospitals. Nearly half felt that the risk of HIV transmission in the clinic was high. Results from this survey show that there is a fair level of knowledge as far as HIV/AIDS is concerned amongst this population (Gachigo & Naidoo, 2001).

1.3.4 KAP amongst non-dental and dental health care workers regarding oral manifestations HIV

Oral health care for HIV and AIDS patients does not differ from non-infected patients. However, HIV infected individuals have a predilection to develop oral lesions as classified by EC Clearinghouse classification (EC-Clearinghouse, 1993). These lesions are opportunistic in nature and are caused by bacteria, virus, fungi and cancer. Routine oral care should be given to the patients with the exception of certain circumstances where it should be modified (Shirlaw et al., 2002).

The majority of the studies (Erasmus et al., 2005; King & Muzzin, 2005; Gachigo & Naidoo, 2001; Rudolph & Ogunbodede, 1999 ; Kaimenyi & Ndung'ũ, 1994a & b; Snyder, 1993) focused on infection control policies and the knowledge, attitude and practices amongst all health care workers. These studies did not examine the levels of knowledge of health care workers on oral manifestations of HIV/AIDS and the management of these lesions. There is a paucity of KAP studies carried out on dental or non-dental health care workers about oral manifestations of HIV.

A study was carried out in Lesotho, with the aim of determining oral health knowledge, attitudes and behaviour among general nurses in Lesotho.

The knowledge of the aetiology and prevention of dental caries, periodontal disease, oral cancer and the oral manifestations of HIV-infection was found to be adequate. Nurses in Lesotho reported positive attitudes towards the provision of oral health education and oral hygiene practices. Most nurses themselves were found to be familiar with the symptoms of oral health needs and their utilisation of the oral health services (Walid et al., 2004).

In another survey done among dental practitioners in South Africa to determine their knowledge and attitudes towards HIV infection, the majority of dentists were aware of the aetiology and transmission of HIV/AIDS and they demonstrated knowledge about the oral manifestations of HIV. However, there were considerable gaps in their understanding regarding the dental management of infected patients. Only 45 % were prepared to continue to care for HIV-infected patients.

In summary, most health care workers both within and outside the dental fraternity have knowledge gaps with regard to HIV/AIDS and have concerns and anxiety about the risk of infection by HIV. This risk results in negative attitudes towards their practices in treating infected patients which may result in discrimination of patients and thus poor management of HIV/AIDS in general and oral lesions in particular.

1.3.5 KAP amongst non-dental health care workers regarding dental/ oral health

Oral lesions associated with HIV/AIDS compromise the oral health in infected patients which becomes worse as their condition progresses (Aldous & Aldous, 1991). Oral lesions further compromise the general health of the patients; firstly, a mouth with infection creates stress on the already compromised immune system and secondly, optimal oral function is needed for eating essential foods in order to maintain the immune system of the already immuno-compromised patients (Aldous & Aldous, 1991). It is therefore imperative that all health care workers involved in patient care should have sufficient oral health knowledge in order for them to be able to manage oral diseases if they are to provide holistic service to patients.

1.3.6 KAP amongst non-dental health care workers regarding oral health

The following studies sought to ascertain the knowledge, attitudes or perceptions and practices of non-dental health care workers with regards to oral health.

Thean et al. (2007), reported on a pilot study to assess the oral health knowledge among staff working in a local nursing home managed by a voluntary welfare organisation in Singapore. They found that nearly all (99.6%) of the respondents felt that oral health care of the elderly was very important. The staff of this nursing home demonstrated positive knowledge of periodontal disease and denture care. However, 55% lacked knowledge of dental caries.

A study done in the nursing homes for the elderly by Marmy and Matt (2003) demonstrated that the nurses look after the daily oral hygiene of the residents. The study showed that these professionals encountered several barriers which prevented them from carrying out their work successfully. For example, the lack of oral health knowledge as well as lack of time and interest on the part of nursing management resulted in them not being able to manage the oral health problems. The nursing staff showed a great interest in furthering their knowledge of dental care but the challenge was the lack of training implementation by management. Dental health enjoyed a low priority in the organisation of nursing homes and thus was not really integrated in the health care programme itself.

A study by Preston et al., 2000 was undertaken in the United Kingdom, in order to determine the knowledge and views of nurses working on acute and rehabilitation care of the elderly wards about oro-dental care. Approximately half of the study population regularly gave advice to their patients about dental care but their knowledge and reasons for providing oral care and advice was often incorrect. The group's understanding of the availability of dental treatment provided by the National Health Service was also often inaccurate. Preston et al. (2000) concluded that a better core knowledge of the oro-dental care of older patients was required by all healthcare professionals who cared for this group of patients.

Rak and Warren (1990), surveyed nurses working with elderly patients in the UK, to assess the nurses' attitude to mouth care, their level of training in this subject, and their level of dental knowledge. The findings from this study revealed a fairly high level of basic training in dental and mouth care matters. There was however, a paucity of specific dental knowledge e.g. there was some confusion over the aetiology and prevention of dental caries and also the difference between gingivitis and periodontitis. In addition, few nurses seemed to be aware of the effects systemic disease and drugs may have on the oral tissues.

Mynors-Wallis and Davis (2004) assessed the oral health knowledge amongst nurses working with elderly people in a local hospital managed by a Primary Care Trust in the United Kingdom, before and after a dental training talk. Twenty members of the nursing staff completed the initial questionnaire and 14 completed it a month later after the talk. There was an increase in the mean number of correct answers from 25% to 34.9% per member of staff 25% to 34.9%. A dental talk to these nurses caring for elderly people in a local hospital resulted in the increase of the level of oral health care knowledge and oral health care of patients .

In addition, a randomised controlled trial was carried out in order to assess the effect of an oral health care education programme (OHCE) on nursing home caregivers. The OHCE intervention significantly improved the knowledge scores and attitude scores of the intervention group over the control group. The main predictors for knowledge and attitude scores were age and dental attendance patterns of the group. The OHCE programme was well received and resulted in improved oral health care knowledge and attitudes amongst the nursing home caregivers (Frenkel & Harvey, 2002).

In USA, Virginia, an investigation was done with the purpose of identifying the oral healthcare role of nurses' aides in nursing homes. Nurses' aides were asked to report on the preventive and referral oral health services they provided, factors that encouraged and discouraged performance of these services, and their perceived knowledge of oral hygiene care procedures. Nurses' aides in nursing homes reported providing preventive oral health services such as mouth rinsing (71%), toothbrushing (63%), and denture cleaning procedures (37%) for nursing home residents. Over 70% of nurses' aides indicated that patient cooperation was a major factor that encouraged their performance but, patient's lack of cooperation discouraged the provision of care by a greater percentage (88%). Aides typically reported suspicious and abnormal manifestations detected in residents' mouths to the nurse in charge of the shift (97.5%). The majority of nurses' aides rated their knowledge of mouth rinses (99%), denture cleaning (99%), toothbrushing (97%), fluoride mouth rinses (90%) and mouth checks (91%) as adequate or excellent. However, a large percentage of nurses' aides rated their knowledge of saliva substitute (45%) and flossing (39%) as poor. Overall the nurses' aides had good knowledge of oral hygiene practices but little knowledge about flossing and saliva substitutes. Thus, the role of the education and training programs for nurses' aides is essential (Hardy et al., 1995).

In summary, most of the studies demonstrated a poor to fair level of knowledge about oral health by health care workers but the reviews also show an interest by health care workers to learn more about oral health care. The knowledge improved after interventions aimed at enhancing their knowledge levels. Most reports also recommend that dental or oral health care must be included in general health care of patients. Their practices or care provided to patients depended on their level of knowledge. Hardy et al. (1995) demonstrated that practices/management improved after interventions aimed at increasing health worker knowledge. Their knowledge of the effects of systemic disease on oral health was not clearly demonstrated in the above studies. It was also illustrated in the above review that numerous KAP studies done throughout the world on all health care workers (dental and non-dental) and HIV reveal diverse knowledge gaps amongst health workers and specific knowledge of oral manifestation of HIV is not demonstrated. The few studies that specified oral manifestation of HIV reveal that health workers have little knowledge about oral manifestations of HIV and have poor practices when it comes to management of the lesions. More training on management of oral manifestations of HIV is thus required for all health workers.

This study was conducted to elicit the levels of knowledge, attitudes and practices about oral lesions in HIV amongst caregivers from the non-dental fraternity who are employed by the NGOs/CBOs in Gauteng.

The data obtained could prove to be very useful for a range of stakeholders involved in home-based care in order plan services appropriately and implement training or educational interventions that will be useful in the management of oral manifestation of HIV. For mouth lesions, certain mouth rinses are recommended for HIV-infected people. The active ingredient, chlorhexidine gluconate, in most mouth rinses has been shown to be effective for most oral lesions (Barasch et al., 2004; Costa et al., 2003; Hunter & Addy, 1987). Other mouth rinse with active ingredient , benzydamine, have been shown to be effective for most oral lesions (Malele et al., 2007; Quane et al., 1998; Edres et al.,1997; Arendorf et al., 1996 ; Turnbull, 1995; Matthews et al., 1987). Any mouth rinse with the above mentioned ingredients can be recommended for oral lesions. Basic simple management procedures can reduce the patient pain and discomfort due to the oral lesions and improve quality of life of patients (Malele et al., 2007).

Chapter 2: Methodology

2.1 Aim

The aim of the study was to determine the knowledge, attitudes and practices regarding common oral manifestations associated with HIV/AIDS of caregivers providing palliative care to HIV positive patients.

2.2 Objectives

1. To determine the knowledge of the caregivers in the NGOs/CBOs providing palliative care in Region 8, CoJ, Gauteng regarding common oral manifestations associated with HIV. of the caregivers in the NGOs/CBOs
2. To assess the attitudes of the caregivers in the NGOs/CBOs providing palliative care in Region 8, CoJ, Gauteng on common oral manifestations associated with HIV.
3. To determine the practices of the caregivers in the NGOs/CBOs in Region 8, CoJ, Gauteng, pertaining to the common oral manifestations associated with HIV.
4. To determine the socio-demographic profile of the caregivers providing palliative care in the NGOs/CBOs in Region 8, CoJ, Gauteng.

2.3 Material and Methods

2.3.1 Study design

A descriptive cross-sectional study was conducted in the mentioned NGOs/CBOs. This method was chosen because it is the best for determining the status quo (Neuman, 1997) in this case, the level of KAP in the caregivers. The knowledge, attitudes and practices about oral lesions associated with HIV infection was described for all caregivers who were based in the palliative care institutions or home-based organisations in CoJ, Region 8.

2.3.2 Study population

The current study was conducted after the Dlamini and Rudolph (2004) study. The purpose of which was to carry out an appraisal of home based care services and HIV/AIDS/TB programmes in the CoJ in order to ascertain the impact of existing programmes and recommend new and effective interventions.

From the desktop analysis performed, there were 30 NGOs and CBOs registered with the Wits Central Health Region in Region 8, an inner city precinct and one of the 11 demarcated regions of the CoJ. Only four centres provided care and support by offering hospice and palliative care services. Thus this study population included all 62 caregivers who worked in the four NGOs/CBOs that provided care and support on palliative care services, no sampling was done.

2.3.3 Data collection

2.3.3.1 Measurement Instrument: Questionnaire

A questionnaire (Annexure II) was developed especially for the study and consisted of Section A, **Socio-demographic information**. Section B, knowledge; Section C, attitudes and Section D, practices on oral manifestations of HIV of caregivers. No questionnaire that would fulfill the objectives of the research question was identified in literature. A special questionnaire as thus designed to fulfill to test all three areas of the study as listed in the objectives. The questionnaire had four sections of closed and open-ended questions. **Section A** obtained information about the following **independent** variables: age, gender, marital status, educational level, employment status, length of time at being a caregiver, training in home-based care, and training in oral health care. Caregivers were also requested to specify the details for the training obtained in the open-ended section. The **dependent** variables were those variables that were observed to change i.e. the KAP of the caregivers in response to the independent variables, specifically training in oral health care.

There were close-ended questions related to ‘**knowledge**’ in **Section B**. These questions were based on the knowledge of common oral manifestation associated with HIV as classified by the European Clearinghouse Classification (ECC) and WHO (EC-Clearinghouse, 1993). Multiple choice questions were avoided as they could result in guessing and therefore give false impression of knowledge of the caregivers.

Knowledge

Knowledge can be simply defined as what one knows about a certain subject. It can be based on belief, justification and experience (Holt, 2005). Sources of knowledge come from different media; books or being taught formally or informally.

Knowledge questions thus ascertained factual information from the respondents about the subject in question i.e. oral manifestations of HIV. Respondents may overstate their knowledge or recognition because knowledge questions can be threatening at times respondents do not want to appear ignorant (Neuman, 1997). To overcome this, open ended questions were asked in Section B, number 2, 8 and 10, respondents were required to elaborate if they had answered *õyes* to number 1, 7 and 9, respectively. Caregivers were asked to respond in a form of *õyes/noõ* to the questions, “*can you identify....*” or “*do you know...*” Furthermore, open-ended responses were required if the response was *õyes* to the “*do you know...*” questions. Caregivers were asked to provide details of their response. This detail was important in verifying their response to check if it correlated with the positive answer.

For the purposes of this study the definition of the lesions were described in everyday language in the questionnaire. Caregivers were not trained prior to the study. The research aimed to ascertain the KAP of the caregivers at that point in time of their care giving service. Questions in the *õKnowledgeõ* Section B were asked in an explanatory descriptive form to avoid using medical jargon in order to accommodate the ancillary or auxillary caregiver as explained in paragraph 1.3.1.1 under Definitions of Terms. Therefore questions were phrased in such a way as to have an appropriate level of understanding for the caregivers. The correct medical terminology was provided in brackets. The following questions were asked:

1. Do you know of any common mouth lesions found in HIV positive patients?
2. If yes, list them.
3. Can you identify oral thrush? (Candidiasis)
4. Can you identify white stripes on the sides of tongue of HIV positive patients?(Hairy Leukoplakia)
5. Can you identify a reddish line on the gums of HIV positive patients?(Linear Gingival Erythema)
6. Can you identify bleeding gums with whitish areas between most teeth and bad breath in HIV positive patients?(Necrotising Ulcerative Gingivitis)
7. Do you know of mouth cleaning advice/instructions to give in HIV positive patients?
8. If yes, give details.
9. Do you know of any referral procedures to follow when dealing with HIV positive patients with mouth problems.
10. If yes, give details.

Attitudes

Attitudes are based on theoretical construct that represents an individual's preference or dislike for an item or idea (Jong, 1993). They can be neutral, positive or negative and one can have an attitude about an event, behaviour or a person. Attitudes are developed based on the affective, behavioural and cognitive responses. Attitudes more often are learnt through observation (Schou & Blinkhorn, 1993). In the study, Section C sought to ascertain the attitudes of caregivers about behaviour or practice, for instance; the statement "The mouth is a difficult area to clean for the patients" is ascertaining attitude about the behaviour. The attitude section was designed to gauge the prevailing beliefs, misconceptions and opinion about the oral manifestations of HIV. **Section C** had six statements that required information about '**attitudes**' of caregivers regarding caring for the mouth of a patient with oral manifestations of HIV. The respondents were asked to indicate whether they agreed or not with the statements. The middle option of 'don't know' was left out. By omitting this middle choice, the author compelled the participants to choose an option and give their opinion (Neuman, 1997). According to Neuman, many people will offer an opinion or response if no middle option is available.

Practices

Practices are the actual actions (giving advice or providing treatment) performed by the caregivers in response to the patients' problems or symptoms based on their knowledge. Again respondents were required to elaborate on their answers to make sure it is in agreement with the correct practice/procedure. The final part of the questionnaire, **Section D** elicited information about '**practices**' of caregivers regarding care/management of the common oral lesions associated with HIV. Caregivers were asked to respond 'yes/no' to questions: "*do you provide action/advice for the following oral problems*" then common oral manifestation associated with HIV were listed.

Caregivers were further requested to write down the said action/advice if they had responded 'yes'. The detail was important in finding the very objective of the study because a simple 'yes/no' response would not give the scope of their practices (Annexure II).

2.3.3.2 Piloting the questionnaire

The newly developed questionnaire composed of 27 questions related to KAP, excluding the socio-demographic data. It was estimated that it would take approximately 15-20 minutes to answer. The questionnaire was piloted at one of the 18 NGOs in the study population which was not included in the sample. This was done to test for reliability, validity, comprehension and the degree to which the questions are interpreted and understood by different individuals, time taken to complete and feasibility.

Reliability deals with the measurement instrument's dependability (Neuman, 1997). If the measure is dependable it means it gives the same result each time the same variable is measured. The responses provided from the questionnaire's items should not vary as a result of the characteristics of the instrument. The questionnaire items should provide the same responses when applied in different time periods. Fifteen caregivers were given the questionnaire to answer. After the questionnaires were completed, the investigator looked at the responses and interrogated the respondents. It was noted in the first questionnaire designed that there was a lot of misunderstanding/misinterpretation of the concepts. Not all respondents understood concepts like "diagnose". This resulted in caregivers not giving the same reliable result. Questions like, "*can you diagnose...?*" were changed to "*can you identify...?*" questions. Questions like "*what practices do you provide for oral thrush?*" were changed to "*what action/advice do you provide for oral thrush?*" for better comprehension of the caregivers.

Validity refers to extent to which the measurement instrument (questionnaire) measures what it is supposed to measure. Did the questionnaire measure the KAP of caregivers on oral lesions in HIV? This is referred to content validity of the questionnaire. The questionnaire was designed to find out about the common oral lesions associated with HIV/AIDS as classified by ECC and WHO (EC-Clearinghouse, 1993). Attempts were made to construct statements in a manner that would be understandable to the caregivers given the definition of the caregivers in paragraph 12.1.1., the idea was to ensure content validity of the questionnaire.

Comprehensiveness of the questions was important for the responses provided by the caregivers. In the piloted questionnaire, the caregivers had difficulty understanding medical jargon common questions were asked by many respondents and explanations had to be given. It was decided during this stage that it is better to include the explanations and leave the correct terminology in brackets i.e. phrase the questions in such way that could be easily comprehended by the respondents.

Completion time.

The initial **time taken** to answer the questionnaire by the last participant was 28 minutes. According to Neuman, 1997, there is no absolute proper length of a questionnaire. The length depends on the survey format and on the respondents' characteristics. A short 3 or 4 page questionnaire (in this study) is appropriate for a general population. After the questionnaire was corrected and re-piloted to a different NGO with 8 caregivers and the time taken to answer was 20 minutes. This time taken to answer the questionnaire seemed sufficient for the purposes of the study.

2.3.3.3 Administering the questionnaire

Data was collected in a form of questionnaires which were taken to the caregivers at the four institutions to complete after providing informed consent (Annexure I).

The investigator sought prior permission and appointment with each of the four institutions management before recruiting the caregivers. Different appointment dates were given for different institutions. On the day of the visit to each of the institutions, access to caregivers was arranged by the management and venue and time was provided to complete the questionnaire. Informed consent was obtained following an explanation of the purpose of the visit. Caregivers were briefed about the investigator's intended research visit by their managers. The questionnaires were administered and completed while the investigator waited.

There were no time limits in answering the questionnaire. Caregivers were encouraged to ask for clarity and ask questions from the investigator. Communications amongst caregivers were discouraged because it was important that individual caregiver's KAP be captured.

2.3.4 Measurement and Data analysis

The Epi Info version 3.3.2 was used for part of the analysis of data. A questionnaire was designed in the Epi Info software and raw data was captured. Summary descriptive statistics describing the profile of the caregivers were computed. StatsDirect software version 2.6.7 was used to determine measures of symmetry in order to ascertain the skewness of data. Since the distribution of the population was not normal, differences in mean age for the two groups of caregivers was determined using Wilcoxon two sample test. Responses to open-ended questions were grouped according to frequencies. Frequency distributions were then determined for all the variables. Two by two (2 x 2) tables were developed for various variables and the Fisher Exact and Chi squared tests were used to test for statistical significance in relation to differences between caregivers trained and not trained on oral health care. A p-value of <0.05 was considered statistically significant.

During the data analysis, it was observed that participants could be placed into two categories: 1) Those that received previous training in oral health care and 2) Those that were not trained on oral health care. To address this potential confounder, the results on the three important outcome variables under study, namely: Knowledge, Attitudes and Practices were presented in the frequency of occurrences and were stratified by whether training in oral health care was received or not.

2.3.5 Ethical considerations

All research conducted should always contain a statement of the ethical considerations involved (Neuman, 1997). Principles that guide the ethics of research; beneficence, non-maleficence and autonomy were upheld at all times. Beneficence and non-maleficence were maintained by ensuring that none of the caregivers or their institutions were subjected to any harm by ensuring that records were kept confidential and anonymous. Respect for the privacy of the caregivers and analysis of their records occurred in privacy without prejudice in order to respect their autonomy. The research was granted ethical approval and clearance without conditions by the Human Research Ethics Committee (Medical) of University of the Witwatersrand, Johannesburg, and clearance certificate number: M050504 was provided (Annexure III).

2.3.6 Limitations

The limitation of the study was that a newly developed questionnaire that has not been tested elsewhere was used for data collection. The reason is that no questionnaire could be found in literature that would fulfill the objectives of the study. Efforts were made to test the newly developed questionnaire for reliability and validity of the content of the questionnaire. The population of the caregivers in the study area of interest was limited to 62. This number made it not possible to compute the associations and correlation. A larger population encompassing more regions in CoJ is recommended for the correlations to be made.

Chapter 3: Results

The caregivers in four organisations that provide palliative care in addition to other services in Region 8, Gauteng, were asked to complete a questionnaire. There were 62 caregivers working in these organisations of which, 52 responded to the questionnaire. The response rate for the study was 84% which was a very good response. The demographics of the 10 non-respondents were not significantly different from the respondents as seen in the list of all caregivers provided for the institutions.

3.1 Socio-demographic data

Data analysis and the results were grouped according to two categories of caregivers; those trained in oral health care (TOHC) and those who did not receive training in oral health care (NTOHC).

Table 3.1: Mean age of caregivers trained (TOHC) and not trained (NTOHC) in oral health care

Variable	Combined (n=52)	Trained in Oral Health Care (n= 34)	Not Trained in Oral Health Care(n=18)	p-value (Wilcoxon Test)
Mean age	39.1	43.5	30.8	*0.002
Std. dev.	14.28	14.14	10.56	
Range	19-65	25-65 years	19-53 years	

* Statistical significance (p< 0.05)

Table 3.1 illustrates that there was statistical significant difference in the mean age for the two groups of caregivers (p<0.005). The high standard deviation values indicate that the two groups of caregivers were very heterogeneous in terms of the age in years.

Table 3.2: Socio-demographic profile of caregivers trained (TOHC) and not trained (NTOHC) in oral health care

Variables	Trained in Oral Health Care (n= 34) n (%)		Not Trained in Oral Health Care (n=18) n (%)		p-value(fisher exact & chi squared tests)
Gender	Male	Female	Male	Female	
	2(5.9)	32(94.1)	5(27.8)	13(72.2)	*0.04 (Fisher Exact)
Marital status	Married	Not married	Married	Not married	
	14(41.2)	20(58.9)	4(22.2)	14(77.8)	0.08 (Chi squared)
Education level	Higher education	Grade 3-12	Higher education	Grade 3-12	
	11(32.4)	23(67.6)	4(22.2)	12(77.8)	0.42 (Fisher Exact)
Employment status	Full time	Part time	Full time	Part time	
	23(67.6)	11(32.4)	17(94.4)	1(5.6)	*0.02 (Fisher Exact)
Work experience	> 1 year	< 1 year	> 1 year	< 1 year	
	20(58.8)	14(41.1)	5(27.8)	13(72.2)	*0.03 (Chi squared)
Training in Home-Based Care	Yes	No	Yes	No	
	34(100)	0(0)	12(66.7)	6(33.3)	*0.001 (Fisher Exact)

There were statistical significant differences in gender, employment status, working as a caregiver and caregivers trained in general home-based care (Table 3.2) Majority (72.2%) of the caregivers NTOHC had less than one year working experience compared with 41.1% of caregivers TOHC ($p=0.03$). Nearly two thirds of caregivers NTOHC were trained in general home-based care as opposed to 100% in TOHC ($p=0.001$). This meant a third (33.3%) of caregivers NTOHC (11% of all caregivers) cared for the patients without any prior training in patient care.

3.2 Responses on knowledge of caregivers regarding oral lesions in HIV positive patients

Table 3.3 illustrates that more than half (56%) of the caregivers NTOHC reported that they did not know the common oral lesions associated with HIV compared to 9% of caregivers TOHC ($p<0.005$). More than 60% of caregivers NTOHC did not know mouth cleaning instructions to give to patients and 78% did not know the referral procedures for HIV positive patients with mouth problems.

Table 3.3 Knowledge about recognition and care of oral lesions in HIV positive patients

Variables	Received training in oral health care (TOHC) n=34		Did not receive training in oral health care (NTOHC) n =18		p-value (Fisher Exact)	Odds Ratio
	No (%)	Yes (%)	No (%)	Yes (%)		
1. Do you know common mouth lesions found in HIV positive patients?	3 (9)	31 (91)	10 (56)	8 (44)	*0.004	12.9
2. Can you identify oral thrush? (Candidiasis)	6 (18)	28 (82)	6 (33)	12 (67)	0.3	2.33
3. Can you identify white stripes on the sides of tongue of HIV positive patients? (Hairy Leukoplakia)	8 (23)	26 (77)	6 (33)	12 (67)	0.5	1.63
4. Can you identify a reddish line on the gums of HIV positive patients? (Linear Gingival Erythema)	6 (17.6)	28 (82.4)	11 (61)	7 (39)	*0.001	7.3
5. Can you identify bleeding gums with whitish areas between most teeth and bad breath in HIV positive patients? (Necrotising Ulcerative Gingivitis)	5 (15)	29 (85)	5 (28)	13 (72)	0.28	2.23
6. Do you know any mouth cleaning advice to give to HIV + patients?	9 (26)	25 (74)	11 (61)	7 (39)	*0.014	4.4
7. Do you know referral procedure to follow in HIV + patients with mouth problems?	9 (26)	25 (74)	14 (78)	4 (22)	*0.003	9.7

The majority of caregivers THOC (91%) reported knowing common mouth lesions more than the caregivers NTOHC (44%), the caregivers THOC were more likely to know common oral HIV lesions ($p<0.05$, OR= 12.9).

The majority of caregivers in both groups (Table 3.3) reported that they could identify what was perceived to be oral thrush (OT) (82% in TOHC, 67% in NTOHC); perceived to be white stripes on the sides of tongue of HIV positive patients (77% in TOHC, 67% in NTOHC) and what was perceived as bleeding gums with bad breath (85% in TOHC and 72% in NTOHC). There was no significant difference in the knowledge levels of these three conditions between the two groups. However there was statistical significant difference in identification of what was perceived to be a reddish line on the gums of HIV positive patients (LGE), 40% of the caregivers NTOHC reported that they could identify the condition compared to 82.4 % of caregivers TOHC ($p=0.001$, OR= 7.3). In summary, there were statistical significant differences in the four of the seven knowledge variables of the caregivers TOHC and those NTOHC. The caregivers TOHC had higher percentage levels of knowledge compared to the caregivers NTOHC.

3.3 Responses on attitudes of caregivers regarding oral lesions in HIV positive patients

Figure 3.1: Attitudes of caregivers regarding oral health care in HIV positive patient

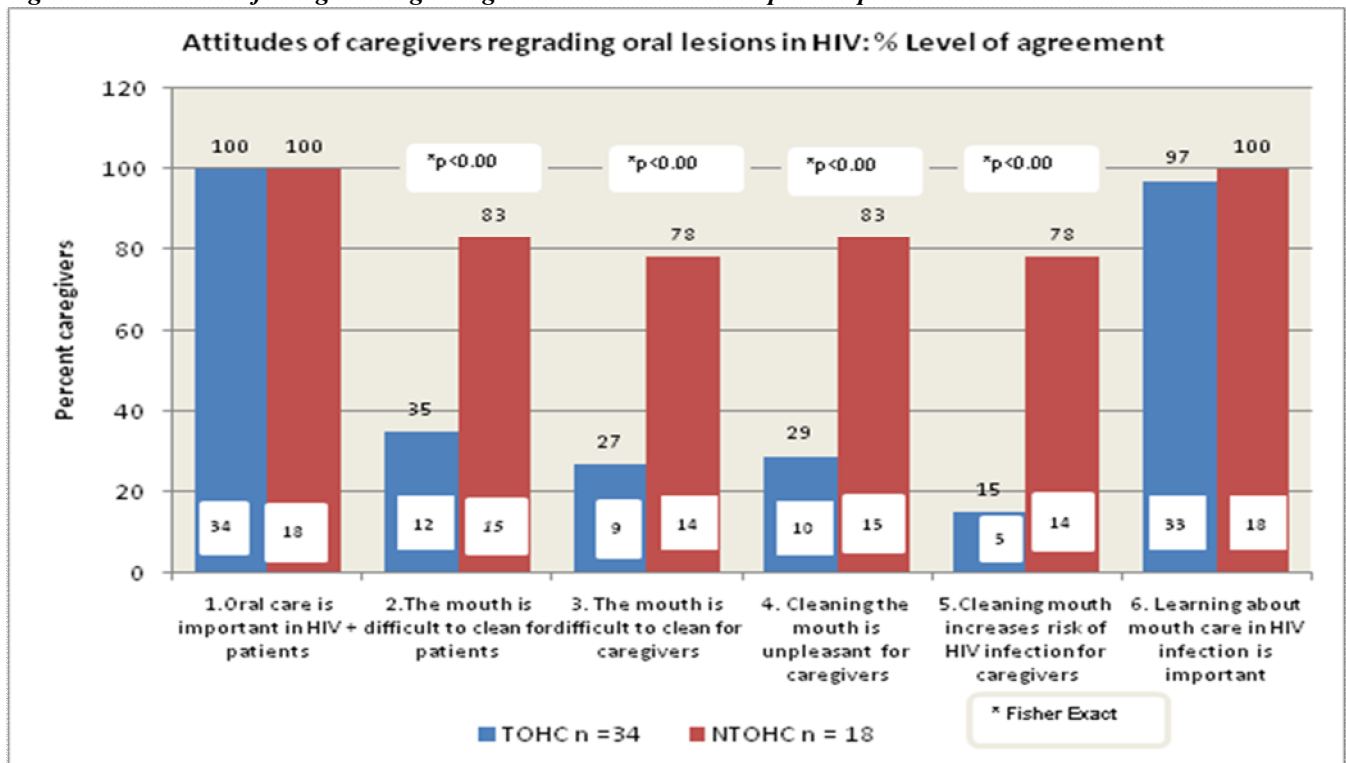


Figure 3.1 provided information on the attitudes of caregivers. All the caregivers agreed that "Oral care is a very important in HIV positive patients" and that learning more about mouth in HIV positive patients was important (97% TOHC, 100% NTOHC).

However, they differed significantly in their responses and opinions about mouth care. For instance, most of the caregivers NTOHC agreed that the "the mouth is a difficult area to clean" for both patients (83%) and caregivers (78%) as compared to the few in the TOHC (35% and 27% respectively) ($p<0.00$). The majority of caregivers NTOHC (78%) were concerned about the infection risk from treating HIV infected patients; they reported that "cleaning the mouth increases the risk of HIV infection for caregivers" compared to 15% of TOHC caregivers who expressed the same concern.

3.4 Responses on Practices of Caregivers on Oral Lesions in HIV Positive Patients

Table 3.4: Practices provided by caregivers regarding oral health care

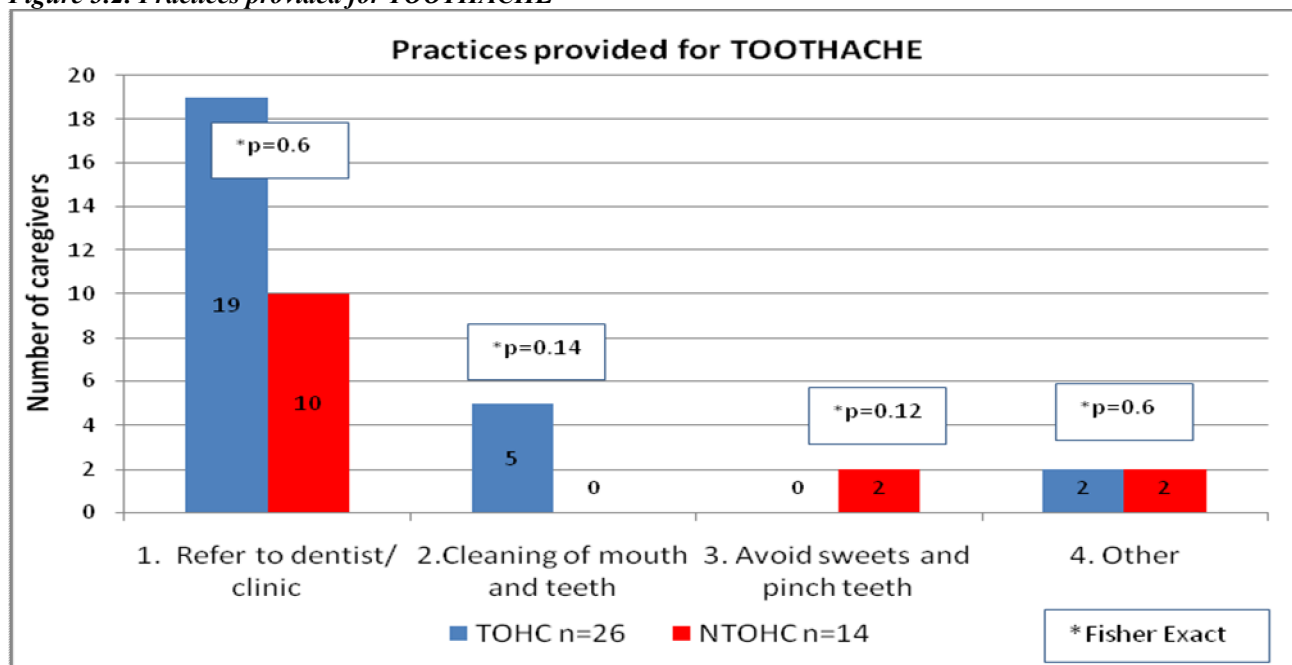
Statement	Combined n=52		Response from caregivers TOHC N=34		Response from caregivers NTOHC N=18		p-value (Fisher Exact)
	Give advice (%)	Don't give advice (%)	Give advice (%)	Don't give advice (%)	Give advice (%)	Don't give advice (%)	
a. Toothache	41	11(21)	26(76)	8(24)	15(83)	3 (17)	0.7
b. Oral thrush	43	9(17)	25(74)	9(26)	18(100)	0 (0)	*0.02
c. Difficulty swallowing	46	6(12)	28(82)	6(18)	18(100)	0 (0)	0.08
d. Dry mouth	39	13(25)	24(71)	10(29)	15(83)	3 (17)	0.5
e. Sores in the mouth	44	8(15)	26(77)	8(23)	18(100)	0 (0)	*0.04
f. Sore on the corners of the mouth/lips	41	11(21)	24(71)	10(29)	17(94)	1 (6)	0.07
g. Bleeding gums	36	16(31)	21(62)	13(38)	15(83)	3 (17)	0.1
h. Painful gums	35	17(33)	20(59)	14(41)	15(83)	3 (17)	0.07
i. Bad breath	41	11(21)	23(68)	11(32)	18(100)	0 (0)	*0.01

* 5% level of significance

Table 3.4 illustrates the reported practices of all caregivers about oral health care for the patients. Caregivers were asked whether they provide action or advice for a list of mouth problems. All caregivers reported providing advice on oral problems regardless of their training in oral health care. Interestingly, higher percentages were noted amongst caregivers NTOHC. Twenty four percent of caregivers TOHC reported giving no advice for patients with toothache. There was a statistically significant difference between both groups of caregivers on regarding the reporting of providing advice for oral thrush, sores in the mouth and bad breath ($p<0.05$).

The responses given by both groups of caregivers mentioned in the underlying results were very variable and numerous and thus were grouped according to frequency.

Figure 3.2: Practices provided for TOOTHACHE



The standard practice for toothache would be referral to the dentist or clinic for further management. The majority of caregivers (Figure 3.2) in both groups reported that they would refer the patients to the dentist/clinic for toothache (73% TOHC, 71% NTOHC). It was important to note that 19.2% of caregivers TOHC reported that they would give oral hygiene to patients in order to improve oral health whereas not one in the untrained group said they would give such an instruction. It was equally important to note the reported practice/advice of pinching teeth with pins and needles by two (14%) of caregivers NTOHC. There were no statistically significant differences between the practices of the two groups of caregivers.

Table 3.5: Practices provided for ORAL THRUSH

Practices Reported By Caregivers for ORAL THRUSH	TOHC n=24 (%)	NTOHC n=17 (%)	p-value (Fisher Exact)
Frequent Oral hygiene, antifungal medication	9(38)	9(53)	0.32
Mouth wash with salty water	7(29)	1(6)	0.06
Go to doctor/clinic for treatment	3(13)	1(6)	0.4
Advice to drink pure juice and soft porridge	0	2(12)	--
Other	5(21)	4(24)	0.6

Fifty three percent of the caregivers NTOHC reported that they would give patients with oral thrush antifungal medication compared with fewer TOHC caregivers (38%), the difference was not statistically different (p=0.32).

Unusual advice was reported by 2 (12%) NTOHC caregivers; such as “drink pure juice and soft porridge” for oral thrush. None of the caregivers in both groups mentioned referral to professionals as practice provided (Table 3.5).

Table 3.6 Practices provided for DIFFICULTY IN SWALLOWING

Practices reported By Caregivers for DIFFICULTY SWALLOWING	TOHC n=26	NTOHC n=15	p-value (Fisher Exact)
Oral hygiene, healthy diet	10(38.4)	2(13.3)	0.08
Medication and soft diet	10(38.4)	11(73.4)	*0.03
Refer to sister/doctor	3(11.5)	0	0.24
Other	3(11.5)	2(13.3)	0.61

*5% level of significance

Table 3.6 represents the practices described by caregivers to manage “difficulty in swallowing”. Most (73.4) % of the caregivers NTOHC reported that they will give the patients who had “difficulty in swallowing” “medication and soft diet” compared to 38.4% of caregivers TOHC ($p < 0.05$). The medication alluded to was not specified. Additionally 38.4% of caregivers TOHC reported that they would recommend a combination of “oral hygiene and give healthy diet”

Table 3.7: Practices provided for DRY MOUTH

Practices Reported By Caregivers for DRY MOUTH	TOHC n=23 (%)	NTOHC n=14 (%)	p-value (Fisher Exact)
Advice to eat pineapple and suck ice cubes , refer	8(34.7)	0	*0.01
Give water or crushed ice	6(26.1)	2(14.3)	0.3
Apply mouth vaseline, eat fruits, oral hygiene	5(21.7)	2(14.3)	0.5
Give them fluids	1(4.3)	10(71.4)	*0.00
Other	3(13)	0	0.2

*5% level of significance

Table 3.7 illustrates the responses of the caregivers regarding their practices for a patient compliant of “dry mouth”. Most (71.4%) of caregivers NTOHC responded that they would give patients fluids compared to 4.3% of caregivers TOHC ($p < 0.00$). A variety of responses came from the caregivers TOHC; 34.7% of them reported that they will stimulate saliva secretion by “giving them pineapple to eat and ice cubes and refer” while 26.1% of them would suggest drinking water or crushed ice. About 21.7% would apply vaseline in addition to “advising on eating fruits, and improving oral hygiene”

Table 3.8: Practices provided for SORES IN THE MOUTH

Practices Reported By Caregivers for SORES IN THE MOUTH	TOHC n=23 (%)	NTOHC n=14 (%)	p-value (Fisher Exact)
Oral hygiene/gargle with mouthwash	9(35)	5(28)	0.8
Refer to doctor/sister	7(27)	3(17)	0.42
No spicy food	2(8)	8(45)	*0.00
Other	8(31)	2(11)	0.12

Table 3.8 illustrates the responses on practices for sores in the mouth. Thirty five percent of caregivers TOHC would advice on oral hygiene for sores in the mouth compared to 28% of caregivers NTOHC. Majority of caregivers NTOHC (45%) would advice patients not to eat spicy food compared to 8% of caregivers TOHC ($p < 0.05$). Few caregivers reported referring patients as a practice (27% in TOHC and 17% in NTOHC) but there was no statistical significance difference.

Table 3.9: Practices provided for BLEEDING GUMS

Practices Reported By Caregivers for BLEEDING GUMS	TOHC n=21 (%)	NTOHC n=14 (%)	p-value (Fisher Exact)
Gargle with salty water, eat fruits	7(33.3)	2(14.3)	0.19
Refer to clinic/doctor/ Report to sister in charge	8(38.1)	0	0.009
Acyclovir cream/tablets	0	5(35.7)	0.006
Soft diet, brush softly/ no fizzy drinks	0	7(50)	0.000
Other	6(28.7)	0	0.033

Half of caregivers (50%) NTOHC said they would advice patients who had bleeding gums to eat soft diet and no fizzy drinks and (35.7%) would advice on the use of acyclovir medication, none of those TOHC would provide this inappropriate and inaccurate advice. However, Once more the caregivers who were TOHC were inclined to refer patients for proper management (38.1%) as opposed to giving erroneous advice. These caregivers were also more inclined to provide advice on oral hygiene (Table 3.9).

Table 3.10: Practices provided for BAD BREATH

Practices Reported By Caregivers for BAD BREATH	TOHC n=23 (%)	NTOHC n=17 (%)	p-value (Fisher Exact)
Clean mouth regularly and give antiseptic	16 (69.4)	4 (23.6)	0.004
Counsel and check for rotten teeth /check diet	0	10 (58.9)	0.000
Gargle with lemon and ginger	0	3 (17.7)	0.07
Other	7(30.1)	0	0.01

Table 3.10 illustrates the responses provided by the caregivers for the patient complaint of "bad breath". Nearly 70% of caregivers TOHC would provide oral hygiene to the patients and then give antiseptic compared to 23.6% of caregivers NTOHC ($p < 0.05$). The majority (58.9%) caregivers NTOHC gave response of "counsel and check for rotten /diet" for management of bad breath and none of the caregivers TOHC provided such a response ($p = 0.00$).

Chapter 4: Discussion

The aim of the study was to determine the knowledge, attitudes and practices of caregivers regarding oral lesions associated with HIV positive patients amongst caregivers in NGOs/CBOs in Johannesburg, Gauteng, SA. This was assessed through a self-administered questionnaire especially designed for the study because no such questionnaire existed in reviewed literature.

4.1 Socio-demographic profile

The results were categorized according to whether caregivers were trained in oral health care (TOHC) or not (NTOHC) to facilitate comparison and difference between participants. There was a statistical significant difference in the **mean age** of the caregivers in both groups. Those caregivers NTOHC were younger than the other group; the two groups were not homogeneous as shown by the large standard deviation. These findings are comparable to the studies by Abernethy et al. (2008) and Takagi (2003) where the caregivers were observed to be older (> 60 years) and widowed. In the current study the caregivers TOHC were older and there was a higher likelihood of them knowing common oral lesions and mouth cleaning advice (Table 3.3). This was comparable to the study by Mynors-Wallis and Davis (2004) where the age of the nursing staff significantly increased the level of oral health care knowledge and hence the oral health care of patients (Mynors-Wallis & Davis, 2004). Most of the caregivers in both groups were female which could be attributed to the fact most of care giving and nurturing kind of careers are traditionally dominated by females because women are usually primary caregivers (Abernethy et al., 2008; Laranaga et al., 2008; Takagi, 2003).

The majority of the caregivers in both groups were '**not married**' (78% NTOHC and 59% THOC). Most caregivers who were 'not married' were in the group NTHOC; this could be attributed to the fact that caregivers NTOHC were relatively younger (mean age 31 years, range 19-53 years) than the other group TOHC. In both groups, many of the caregivers had a relatively low **level of education** and were reported to be schooled up to Grade 12. About a third of the caregivers studied beyond Grade 12 and even fewer (22.2%) for those caregivers NTOHC; the difference was not statistically significant.

The possible reasons that most caregivers were of lower education level could have been attributed to traditionally, care giving profession has recruited lay people where care and nurturing characteristic were important because of the nature of hospice/home-based care work is dealing with very sick and sometimes dying patients (Takagi, 2003; Abernethy et al., 2008).

The majority of the caregivers were **employed on a full time basis** (68% in TOHC and 94% in NTOHC). The institutions which employed the caregivers received funding at the time of the study from the Wits Central Health Region (51%), the private Sector (43%) and the National & Gauteng Departments of Social Services (6%); (Dlamini & Rudolph, 2004). This funding could explain why most of the caregivers were full time employees at the four institutions.

The length of the work experience one has may result in improved efficiency and productivity (de la Cruz et al., 2004). The majority (72.2%) of the caregivers NTOHC had fairly brief **working experience** (less than one year) compared to those caregivers TOHC (41.1%) and the difference was statistically significant. This could explain why the former caregivers knew less about oral lesions on HIV compared to the latter. Longer (more than one year) working experience enables caregivers to be exposed for a longer period to same oral health problems and thus will be more familiar with the oral lesions as opposed to those less exposed. These associations were not done for this population because of the limited size of the population

All of caregivers TOHC and two thirds of caregivers NTOHC group were **trained in general home-based care** which is a basic requirement of care-giving institutions. Capacity development as informed by national guidelines was a prerequisite for engagement in comprehensive care and support for people living with HIV/AIDS. To enable training of NGOs/CBOs care workers, in 2003/4, the city of Johannesburg allocated a budget for organisations involved in the training of NGOs and CBOs caregivers (Dlamini & Rudolph, 2004). However, it was a concern that about a third of caregivers NTOHC and 11% of all caregivers did not receive training on general home-based care which meant that the caregivers cared for the patients without any prior training/preparation or schooling in patient care.

The findings of this study are however in contrast to the Dlamini & Rudolph (2004) study, where it was shown that on average 75% of NGOs/CBOs caregivers lack the expertise to provide basic nursing care and thus the inability to provide comfort measures for people infected with HIV and to protect themselves from infection.

4.2 KAP on Oral Lesions in HIV.

4.2 Knowledge

From the review of literature undertaken, there were several KAP studies which have been undertaken on different categories of health workers to assess their general knowledge of HIV/AIDS and not on the oral manifestations of HIV infection. Several studies from both developed and developing countries demonstrated that health workers seem to have little or poor knowledge on HIV and have low willingness to care for infected patients (Infante et al., 2006; Aisen & Shobowale., 2005; Hentgen et al., 2002; Brusafero et al., 1997 and Adelekan et al., 1995). In contrast, the current study determined the knowledge, attitudes and practices of non-dental health care workers about oral manifestation of HIV.

Those caregivers who were trained in oral health care reported having higher knowledge levels on four of the seven variables of oral problems in HIV as compared to those who were not trained in oral health care. There was a higher likelihood as shown by odds ratios in Table 3.3 of these four knowledge variables and training in oral health care. Caregivers TOHC were more likely to know common oral lesions, cleaning advice, to recognize a reddish line of the gums of the patients and referral procedures for patients with mouth problems. This finding in the current study is in agreement with the study by Mynors-Wallis & Davis (2004), where a dental talk (training in oral health care) to a group of nursing staff caring for elderly people in a local hospital produced a significant increase in the level of oral health care knowledge by the nursing staff and hence the oral health care of patients (Mynors-Wallis & Davis, 2004). Results from this study are also similar to a study by Frenkel and Harvey (2002) where oral health care education (OHCE) programme was the main predictor for knowledge and attitude scores. The OHCE resulted in improved oral health care knowledge and attitudes amongst the nursing home caregivers (Frenkel & Harvey, 2002).

4.3 Attitudes

In general the majority of caregivers NTOHC reported negative attitudes regarding oral care of HIV positive patients. Only few of caregivers who were NTOHC disagreed that the "The mouth is a difficult area to clean" for both patients (17%) and caregivers (22%). Many of them also agreed that "Cleaning the mouth is an unpleasant task for a caregiver" (Figure 3.1) and they were worried about the infection risk.

Negative attitudes are usually associated with little or no knowledge about certain aspects. According to Jong, (1993) using the behavioural model, necessary support (training) and knowledge are important in changing attitudes. This could be the reason for the positive attitudes of the trained caregivers. In a randomised controlled trial carried out in order to assess the effect of an oral health care education programme (OHCE) on nursing home caregivers. The OHCE intervention significantly improved the knowledge scores and attitude scores of the intervention group over the control group. The OHCE programme was well received and resulted in improved oral health care knowledge and attitudes amongst the nursing home caregivers (Frenkel & Harvey, 2002).

The attitudes of the caregivers about infection risk were worrying. Majority of caregivers NTOHC (78%) agreed that "cleaning the mouth increases the risk of HIV infection for caregivers" compared to 15% of caregivers TOHC ($p < 0.00$). Equivalent findings of disturbing attitudes were shown in a KAP survey performed to analyse knowledge, perception of risk, attitudes and behaviour towards HIV infection among health workers in two hospitals in the North-East of Italy. There was a high perception of the risk of acquiring HIV infection through occupational exposure. A significant portion of health workers showed low willingness to care for HIV-positive patients and negative behavioural attitudes persisted (Brusafero et al., 1997). Similar findings of poor or negative attitudes were shown in the following studies: Infante et al., (2006) 75%; Aisien & Shobowale, (2005) 40%; King & Muzzin (2005), majority; Erasmus et al., (2005), majority; Hentgen et al., (2002) 20%; Kiatura et al., (1997) 70%; Adelekan et al., (1995) 33% ; McCartan & Samaranayake, (1991) 59% ; where health care workers felt they are at risk of infection of HIV when attending to HIV positive patients.

4.4 Practices

Various practices were reported by both groups of caregivers. At times caregivers NTOHC reported providing appropriate advice despite not being trained. For instance, most caregivers NTOHC (71%) would refer cases of toothache to a dentist or clinic. This was not surprising though, because, it is general knowledge amongst the general community that dentist deal with tooth problems. Unusual inappropriate practice of pinching teeth with needles was mentioned by a few caregivers NTOHC. Several unsuitable practices were mentioned throughout for all other problems highlighted in the questionnaire by the few caregivers NTOHC.

- **Practices For Oral Thrush**

It is important that oral thrush is treated speedily to prevent patients from pain and thus interrupted eating patterns which will further compromise their condition (Aldous & Aldous, 1991). It usually presents with white plaques on the tongue, palate or inner cheek. Infection in advanced immune-deficiency may spread into esophagus and trachea and may cause difficult or painful swallowing (Evian, 2003). The standard management of oral thrush includes drug therapy with anti-fungals and/or referral to professionals for further management. This current study reported that both groups of caregivers would provide antifungal and mouthwash. A few of those caregivers NTOHC reported providing unusual advice on the use/drinking pure juice.

- **Practices for Difficulty in Swallowing**

Difficulty in swallowing in patients is multifactorial. Supportive treatment like analgesics and soft diet before referral to professional/clinic is recommended (Evian, 2003). Caregivers from both groups reported providing supportive treatment advice of eating soft diet or medication. It is hoped that the medication would have been prescribed by the attending doctor. Those caregivers TOHC would also advise on oral hygiene before referring patients to professional for proper diagnoses and management. This indicates that the caregivers are aware of importance of good oral hygiene.

- **Practices for Managing a Complaint of Dry Mouth**

The problem of dry mouth can be symptomatic of various diseases or infections (including HIV/AIDS, Diabetes, Anemia, Sjögren's syndrome, rheumatoid arthritis, cystic fibrosis, the mumps or a stroke) or could be a side effect of medication (Antihistamines, pain relievers, blood pressure medications, antidepressants, chemotherapy, mental disorders, asthma, epilepsy , etc.) or lifestyle (smoking, drinking caffeine, alcohol or breathing via the mouth) can all cause dry mouth (National Institute of Dental and Craniofacial Research). Dry mouth can also lead to halitosis and if it persists may make an individual susceptible to gingival infections and dental caries. Proper underlying cause must be diagnosed by professional following referral. Supportive treatment aims at stimulating saliva secretion to reverse the symptom or patients are advised to drink fluids (Evian, 2003).

Interestingly, the caregivers TOHC mentioned giving advice of stimulating saliva secretion by sour fruit or crushed ice. The caregivers NTOHC would also advise on drinking plenty of fluids. The reported advice from the caregivers would not harm the patients however, if referral is delayed, the underlying problem could go undiagnosed and untreated. It is import that if caregivers are not professionals, the advice they are giving should be in line with professional instruction.

- **Practices for Sores in the Mouth**

The standard management for a patient complaint of sores in the mouth would be proper diagnosis and treatment. Ulceration in HIV infected patients could be viral, bacterial, fungal and neoplastic in origin (EC-Clearinghouse, 1993). Supportive treatment and referral for proper management is thus recommended. Both groups of caregivers reported that they would provide oral hygiene instructions to the patients before referring them for better management. Those not trained also thought that advising patients to stop using spicy food could benefit the patients. Ulceration in HIV infected patients is a common problem and cause pain and discomfort for the patients (Arendorf et al., 1996, Norval, 2004). It is thus important and interesting to note that it was handled appropriately by the caregivers. The preferred practice for this problem would be to refer for proper investigation and management.

- **Bleeding Gums and Bad Breath**

Standard management for bleeding gums would be diagnosis of the underlying problem and treatment. Bleeding gums could be symptom of infections, trauma and hormonal or neoplastic pathology. Standard management is to identify the underlying problem and treat. Supportive treatment of oral hygiene improvement by regular brushing and adjunct use of antiseptic mouth rinses and referral to dentist for professional scaling and polishing is advised. Occasionally bleeding gums may result in halitosis (Rachanis, 2001). The recommended management of bad breath is diagnosis of the underlying etiology and treatment of bleeding gums. Thus management should include supportive care like mouth hygiene, antiseptic mouth rinses and referral. Few of the caregivers NTOHC reported that they would 'check for rotten teeth' this response assumes that decayed teeth are the only cause of halitosis it is however not incorrect but it excludes other solutions. More than 20% of the caregivers TOHC reported that they do not provide advice or do anything for the patients who presented with toothache (24%), painful gums (26%), bad breath (23%) and bad taste in the mouth (23%) despite their training in OHC. This finding is worrying and it could indicate that knowledge does not always translate to behaviour change, learning can occur without change in behaviour as illustrated by the social learning theory (Schou & Blinkhorn, 1993) .

The fact that most caregivers reported providing some practices to patients does not necessarily mean the practices were correct or within standard guidelines. For instance, 73.4 % of the caregivers NTOHC reported that they will give the patients who had 'difficulty in swallowing' medication and soft diet compared to 38.4% of caregivers TOHC instead of referring the cases for proper investigation and management. The above responses would be proper if caregivers are not diagnosing the cause by themselves but are carrying out the instruction of a professional. An additional 38.4% of caregivers TOHC they would advice on 'oral hygiene, give soft diet and refer' for 'difficulty in swallowing' In the above illustration it would be preferable to provide supportive care and refer to professionals as opposed to treating the symptom because there could be many reasons why patients experience the symptom in question. These findings are in agreement with a study by Preston et al., (2000) where approximately half of the study population regularly gave advice to their patients about dental care but their knowledge and reasons for providing oral care and advice was often incorrect.

The group's understanding of the availability of dental treatment provided by the National Health Service, in UK, was also often inaccurate. It was concluded that a better core knowledge of the orodental care of older patients was required by all healthcare professionals who cared for this group and referral would be the best course of action if health care workers are in doubt (Preston et al., 2000).

In general caregivers TOHC were more inclined to provide a variety of supportive care in form of oral hygiene, regular salty water gargle and use of antiseptics for toothache, bleeding gums, bad breath and difficulty in swallowing compared to those NTOHC. These practices could be attributed to receiving formal training on oral health care. These caregivers (TOHC) were also more inclined to refer cases of (bleeding gums, painful gums, etc.) compared to caregivers NTOHC.

Incorrect practices reported in this study could be corrected by increasing knowledge on basic oral health and oral manifestation of HIV through a training workshop. A dental talk to a group of nursing staff caring for elderly people in a local hospital produced a significant increase in the level of oral health care knowledge and oral health care of patients, knowledge improved practices in that study (Mynors-Wallis & Davis, 2004).

4.5 Conclusion

The findings of the study did determine socio-demographic profile of the caregivers and the knowledge, attitudes and practices of the caregivers in the four palliative institutions in Region 8, CoJ, Gauteng. The majority of caregivers in both groups were female, were employed full-time as opposed to part-time, those caregivers TOHC had higher mean age, more than one year working experience and were trained in general home-based care compared to the caregivers NTOHC.

The caregivers trained in oral health care had to some extent better knowledge levels because they had higher knowledge levels on four of the seven variables of oral problems in HIV as compared to those who were not trained in oral health care. The attitudes of the caregivers NTOHC were that the majority reported that caring for the mouth of HIV positive patients is an unpleasant difficult task and poses an infection risk to the caregivers while these concerns were expressed by the minority of caregivers TOHC ($p < 0.05$).

This implied a negative sentiment by the caregivers NTOHC with statistical significance. Both groups of caregivers had the opinion that oral care is important in HIV care and they would like to know more about oral care for HIV positive patients. Practices performed by caregivers NTOHC were appropriate for **dry mouth, difficulty in swallowing** but was inappropriate for bleeding gums and bad breath while those caregivers TOHC provided appropriate advice/practices for **oral thrush, bad breath, bleeding gums, dry mouth** with statistical difference ($p < 0.05$).

There was no difference in the practices provided for toothache, referring for sores in the mouth and difficulty swallowing for both groups of caregivers. This implied that caregivers TOHC provided appropriate practices on more occasions than those NTOHC. A third of the caregivers who were NTOHC did not receive basic home-based care training.

4.6 Recommendations

Bearing in mind the limitations of KAP surveys and the cross sectional design of the study, the following recommendations were made:

- Training in general home-based care be a prerequisite before caregivers can be allowed to interact with patients in order to provide proper supportive care.
- Training in oral health care and refresher courses for those trained must be incorporated into the programme of all caregivers working in palliative institutions because it will provide specialised knowledge about oral health and oral lesions in HIV and thus improve their current knowledge, attitudes and practices.
- A larger study extended to other regions or province is recommended so that association and correlations between age, work experience, education level, etc and caregivers can be performed.
- Training workshops should be initiated in all the NGOs/CBOs providing palliative care and support and other institutions in order not to further disadvantage the users of these facilities.

References

- Abernethy, A., Burns, C., Wheeler, J., Currow, D. (2008). Defining distinct caregiver subpopulations by intensity of end-of-life care provided. *Palliative Medicine*, Nov 21.
- Adelekan, M.L., Jolayemi, S.O., Ndom, R.J., Adegboye, J., Babatunde, S., Tund-Adimode, M., Yusuf, O., Makanjuola, A.B. (1995). Caring for people with AIDS in Nigerian teaching hospital: Status, Attitudes and Knowledge. *Aids Care*, 7 Suppl 1:S63-72.
- Aisien, A.O., Shobowale, M.O. (2005). Health care workers' knowledge on HIV and AIDS: Universal precautions and attitude towards PLWHA in Benin-City, Nigeria. *Niger Journal of Clinical Practice*, Dec; 8(2):74-82.
- Aldous, J.A., Aldous, S.G. (1991). Management of oral health for the HIV-infected Patient. *Journal of Dental Hygiene*, 65: 143-145.
- Andrien, M. (1994). Social communication in nutrition: Methodology for intervention Development Support Communication Branch Information Division Nutrition Programmes Service Food Policy and Nutrition Division Food and Agriculture organisation (FAO)-United Nations.
- Arendorf, T.M., Solomon, C., Shaikh, A., Mills, G. (1996). Benzydamine hydrochloride (Andolex) improves oral mucosal health in the immunocompromised patients. *South African Medical Journal*, 86(9): 1136-1137.
- Arendorf, T.M., Bredekamp, B., Cloete, C.A.C., Sauer, G. (1998). Oral manifestations of HIV infection in 600 South African patients. *Journal of Oral Pathology and Medicine*, 27:176-179.

Bajomo, S. (2004). The impact of oral manifestations of HIV/AIDS on quality of life of patients living with HIV/AIDS South African Division, IADR 2004, Journal of Dental Research.

Barasch A., Safford M.M., Dapkute-Marcus I., Fine D.H. (2004). Efficacy of chlorhexidine gluconate rinse for treatment and prevention of oral candidiasis in HIV-infected children: a pilot study. Oral Surgery Oral Medicine Oral Pathology Oral Radiology Endodontics, Feb;97(2):204-7

Brusaferro, S., Martina, P., Puzzolante, L., Gasparini, V. (1997). Epidemiological study on knowledge, attitudes and behaviour of health care workers with respect to HIV infection. Medicina del Lavoro, Nov-Dec; 88(6):495-506.

Centre for Health Systems Research & Development. (2002). Strengthening local government and civic responses to the HIV/AIDS epidemic in South Africa. Available at <http://www.ouvs.ac.za/faculties/humanities/chsrd> [Accessed August 2007]

City of Johannesburg HIV/AIDS Programme (2004). Joburg City Website www.coj.gov.za [Accessed June 2007]

Costa, E.M., Fernandes, M.Z., Quinder, L.B., de Souza, L.B., Pinto LP. (2003). Evaluation of an oral preventive protocol in children with acute lymphoblastic leukemia. Pesqui Odontology, Apr-Jun; 17(2):147-50.

dela Cruz, G.G., Rozier, R.G., Slade, G. (2004). Dental screening and referral of young children by paediatric primary care providers. Pediatrics, Nov; 114(5): e642-52.

Department of Health (2000). HIV/AIDS and STD strategic plan for South Africa 2000-2005. Pretoria: Department of Health.

Dlamini S., Rudolph M.J. (2004). Impact of NGOs/CBOs Providing Care and Support for People Infected & Affected by HIV/AIDS in Region 8, City of Johannesburg.

EC-Clearinghouse on Oral Problems Related to HIV Infection and WHO Collaborating Centre on Oral Manifestations of the Immunodeficiency Virus. (1993). Classification and diagnostic criteria for oral lesions in HIV infection. *Journal of Oral Pathology and Medicine*, 22: 289-91.

Edres, M.A., Scully, C., Gelbier, M. (1997). Use of proprietary agents to relieve recurrent aphthous stomatitis. *British Dental Journal*, 182(4):144-146.

Erasmus, S., Luiters, S., Brijlal, P. (2005). Oral Hygiene and dental student's knowledge, attitude and behaviour in managing HIV/AIDS patients. *International Journal of Dental Hygiene*. Nov;3(4):213-7.

Evian, C. (2003). *Primary AIDS Care*. 4th Edition. Jacana Media, Fishwicks the Printers, Durban

Frenkel, H., Harvey, I., Needs, K. (2002). Oral health care education and its effect on caregivers' knowledge and attitudes: a randomised controlled trial. *Community Dental Oral Epidemiology*, Apr;30(2):91-100.

Gachigo, J.N., Naidoo, S. (2001). HIV/AIDS: the knowledge, attitudes and behaviour of dentists in Nairobi, Kenya. South African Dental Journal, Dec;56(12):587-91.

Gauteng AIDS Programme Annual Report 2004/05. www.pgp.gov.za/docs/report/2004 [Accessed October 2007]

Gift, H.C., Redford, M. (1992). Oral health and the quality of life. Clinics in Geriatric Medicine, 8:673-683.

Hardy, D.L., Darby, M.L., Leinbach, R.M., Welliver, M.R. (1995). Self-report of oral health services provided by nurses'aides in nursing homes. Journal of Dental Hygiene, Mar-Apr;69(2):75-82.

Hentgen, V., Jaureguiberry, S., Ramiliarisoa, A., Andrianantoandro, V., Belec, M. (2002). Knowledge, attitude and practices of health personnel with regard to HIV/AIDS in Tamatave (Madagascar) Bulletin for Social Pathology Exot, Jun;95(2):103-8.

Holt, T. (2005). Theory of knowledge. <http://www.theoryofknowledge.info/> [Accessed October 2008]

Human Science Research Council. South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005 <http://www.hivan.org.za> [Accessed 2 December 2006]

Hunter, L., Addy, M. (1987). Chlorhexidine Gluconate mouthwash in the management of minor aphthous ulceration. British Dental Journal, 162:106-110.

Infante, C., Zarco A., Cuadra, S.M., Morrison, K., Caballero, M., Bronfman, M., Magis, C. (2006). [HIV/AIDS-related stigma and discrimination: the case of health care providers in Mexico] *Salud Publica Mexico*, Mar-Apr; 48(2):141-50.

Jong, A. (1993). *Community Dental Health*. Mosby Year book, Missouri

Kaimenyi, J.T., Ndungũ, F.L. (1994a). Knowledge, practices and attitudes towards HIV positive and AIDS patients among dental auxiliaries. *East African Medical Journal*, May; 71(5):304-10.

Kaimenyi, J.T., Ndungũ, F.L. (1994b). Knowledge, attitudes and practices towards HIV positive and AIDS patients among public service dentists in Nairobi. *African Journal of Health Science*, Aug; 1(3):116-121.

Kiatura, H., Adachi, N., Kobayashi, K., Yamada, T. (1997). Knowledge and attitudes of Japanese dental health care workers towards HIV-related disease. *Journal of Dentistry*, May-Jul; 25(3-4):279-83.

King, T.B., Muzzin, K.B. (2005). A national survey of dental hygienists' infection control attitudes and practices. *Journal of Dental Hygiene*. Spring, 79(2):8. Epub 2005 Apr 1.

Laranaga, I., Martin, U., Bacigalupe, A., Begiristain, J.M., Valderrama, M.J., Arregi, B. (2008). Impact of informal care giving in caregivers' health and quality of life: analysis of gender equalities. *Gac Sanit*, Sep-Oct; 22(5): 443-50.

Lim, A.A., Leo, Y.S., Lee, C.C., Robinson, A.N. (2002). Oral manifestations of human immunodeficiency virus (HIV) - infected patients in Singapore. *Annals of Academic Medicine in Singapore*, 30: 600-606.

Malele, Y., Rudolph, M.J., Yengopal, V. (2007). An assessment of the effectiveness of Andolex-C ® mouth rinse on oral palliation in HIV-infected patients. [Thesis] Johannesburg: University of Witwatersrand

Marmy, M., Matt, F. (2003). [Oral hygiene knowledge of caregivers in a psycho-geriatric home] *Schweiz Monatsschr Zahnmed*, 113(7):787-800.

Matthews, R.W., Scully, C.M., Levers, B.G., Hilsop, W.S. (1987). Clinical evaluation of benzydamine chlorhexidine, and placebo mouthwashes in the management of recurrent aphthous stomatitis. *Oral Surgery Oral Medicine Oral Pathology*, 63: 189-191.

McCartan, B.E., Samaranayake, L.P. (1991). Oral care of HIV infected patients: the knowledge and attitudes of Irish dentists. *Journal of Ireland Dental Association*, 37(2):41-3.

Mynors-Wallis, J., Davis, D.M. (2004). An assessment of the oral health knowledge and recall after a dental talk amongst nurses working with elderly patients: a pilot study. *Gerodontology*, Dec; 21(4):201-4.

National Institute of Dental and Craniofacial Research. NIH Publication No. 99-3174. www.colgate-palmolive.com [Accessed December 2007]

Neuman, W.L. (1997). Social Research Methods: Qualitative and Quantitative Approaches, 3rd edition. Allyn & Bacon, Needham Heights, MA

Norval, D.A. (2004). Symptoms and sites of pain experienced by AIDS patients. South African Medical Journal, ;94 (6): 450-454.

Preston, A.J., Puneekar, S., Gosney, M.A. (2000). Oral care of elderly patients: nurses' knowledge and views. Postgraduate Medical Journal, Feb; 76(892):89-91.

Quane, P.A., Graham, G.G., Zielger, J.B. (1998). Pharmacology of benzydamine. Inflammopharmacology, 6:95-107.

Rachanis, C. (2001). Looking into the mouth- oral manifestations of HIV Infection. SA Journal of HIV Medicine, August: 27-31.

Rak, O.S., Warren, K. (1990).An assessment of the level of dental and mouth care knowledge amongst nurses working with elderly patients. : Community Dental Health, Sep; 7(3):295-301.

Ramirez-Amador, V., Esquivel-Pedraza, L., Sierra-Madero, J., Ponce-de-Leon S. (1998). Oral manifestations of HIV infection by gender and transmission category in Mexico City. Journal of Oral Pathology and Oral Medicine, 27: 135-140.

Rudolph, M.J., Ogunbodede, E.O. (1999). HIV infection and oral health care in South Africa. South African Dental Journal, Dec;54(12):594-601.

Schou, L., Blinkhorn, A. (1993). Oral Health Promotion. 4th Edition. Oxford University Press

Shirlaw, P.J., Chikte, U, MacPhail L., Schmidt-Westhausen, A. (2002). Oral and dental care and treatment protocols for the management of HIV-infected patients. Oral Diseases, 8 Suppl. 2: 136-143.

Smith, H.L. (1993). On the Limited Utility of KAP-style survey data in the practical epidemiology of AIDS, with reference to the AIDS epidemic in Chile. Health Transition Review, Vol. 3 (1): 1-15.

Snyder, G.A. (1993). Pennsylvania dental hygienists' knowledge, attitudes, and infection control practices in relation to AIDS and AIDS patients. Journal of Dental Hygiene, May-Jun; 67(4):188-96.

Takagi, E. (2003). Gender Dynamics and Family Caregiving in Japan: Paper presented at the annual meeting of the American Sociological Association, Atlanta Hilton Hotel, Atlanta, GA, August 16, 2003. http://www.allacademic.com/meta/p107418_index.html [Accessed September 2008]

Thean, H., Wong, M.L., Koh, H. (2007). The dental awareness of nursing home staff in Singapore - a pilot study. Gerodontology, Mar; 24(1):58-63.

Turnbull, R.S. (1995). Benzylamine Hydrochloride (Tantum) in the management of oral inflammatory conditions. Journal of Canadian Dental Association, 61(2): 127-134.

Walid, E.I., Nasir, F., Naidoo, S. (2004). Oral health knowledge, attitudes and behavior among nursing staffing Lesotho. South African Dental Journal, 59: 288-292.

Yengopal, V. (2003). HIV and Socio-dental Indicators: A Case-Control Study Using the Oral Health Impact Profile [thesis-unpublished]. Cape Town: University of Stellenbosch

Annexure I

UNIVERSITY OF WITWATERSRAND: SCHOOL OF ORAL HEALTH SCIENCES

INFORMED CONSENT FOR CONDUCTING RESEARCH

Dearë ë

My name is Dr Yolanda Malele. I am a dentist from the School of Public Health: Division of Public Oral Health, University of Witwatersrand. We will be conducting research regarding knowledge and practices of caregivers about oral lesions in HIV amongst caregivers working in NGOs and CBOs (Non-governmental organization and Community-based organizations) in City of Johannesburg. The research is expected to last for a month.

We kindly request you to answer a questionnaire which seeks information regarding your knowledge and practices and little information about yourself. The aim here is to try and establish how much information you have and what practices you perform regarding oral lesions in HIV.

The entire questionnaire will take 15 minutes to answer. All the information you give us about yourself will be strictly confidential and will be kept safe and secure at the university. You will not be identified by name we will only record the number on the form to ensure anonymity.

You are completely free to take part or not to take part in the study. If you decide that you do not want to be part of the study, this will not be held against you and will not be disadvantaged in any way.

If you would like to take part in the study, please sign the form below to allow us to proceed with administering the questionnaire. If you would like to withdraw from the study at any point or for any reason, please feel free to do so and no questions will be asked.

If you have any questions or queries or would like more information about the study please contact Dr Y Malele on telephone number (011) 7172631/7172593; fax (011) 7172625; e-mail maleley@sph.wits.ac.za or after hours on (083 780 0907).

Thank you for your cooperation

Yours sincerely
Dr Y Malele

I agree to participate in the study.

Name:
(In block letters)

.....
(Signature)

Date:

Annexure II

Questionnaire to Elicit Knowledge, Attitudes and Practices about Oral Lesions associated with HIV positive patients by caregivers

Institution.:.....

Record No.:.....

Section A: Personal and Demographic Details

1. Age_____ years
2. Gender: ☐ Male ☐ Female
3. Marital status: ☐ Married ☐ Single ☐ Separated ☐ Divorced ☐ Widow
4. Employment status: ☐ Employed P/T ☐ Employed F/T ☐ Unemployed ☐ Retired ☐ Student
5. Highest educational level attained : ☐ No formal education ☐ Grade 1to 3 ☐ Grade 4 to 8 ☐ Grade 9 to 12 ☐ Higher education (University, Technikon etc.)
6. How long have you been a caregiver? : ☐ 0-6 months ☐ 6-12months ☐ 1-3 years ☐ 4 years and above
7. Did you get training in general home-based care? : ☐ Yes ☐ No
8. What kind of training?
List type of courses offered
 - a. _____ , _____
 - b. _____ , _____
 - c. _____ , _____
9. What was the impact of training? _____ .
10. For how long? ☐ 0-6 months ☐ 6-12months ☐ > 12 months
11. Did you get training in oral health care? : ☐ Yes ☐ No
12. If yes to Q.11, where were you trained? _____ ...

Section B: Knowledge about recognition and care of oral lesions in HIV positive patients

Please indicate with and X

	Statement	Yes	No
1.	Do you know of any common mouth lesions found in HIV positive patients?		
2.	If yes, list them • • •		
3.	Can you identify oral thrush? (Candidiasis)		
4.	Can you identify white stripes on the sides of tongue of HIV positive patients (Hairy Leukoplakia)		
5.	Can you identify a reddish line on the gums of HIV positive patients? (Linear Gingival Erythema)		
6.	Can you identify bleeding gums with whitish areas between most teeth and be HIV positive patients? (Necrotising Ulcerative Gingivitis)		
7.	Do you know of mouth cleaning advice/instructions to give in HIV positive patients?		
8.	If yes, give details/name it		
9.	Do you know of any referral procedures to follow when dealing with HIV positive patients with mouth problems?		
10.	If yes, give details/name it		

Section C

	Statement	Agree	Disagree
1.	Oral care is a very important in HIV positive patients		
2.	The mouth is a difficult area to clean for the patients.		
3.	The mouth is a difficult area to clean for the caregivers.		
4.	Cleaning the mouth is an unpleasant task for the caregiver.		
5.	Cleaning the mouth in HIV positive patients increases risk of infection for the caregivers.		
6.	Learning more about providing mouth care in HIV positive patients is important.		

Section D: Practices regarding oral care in HIV positive patients

		YES	NO	Don't know
I	What are the commonly reported mouth complaints? (you may tick more than one)			
a.	Toothache			
b.	Oral thrush			

	(if yes,)Specify what kind of action or advice ë ë ë ë ë ë ë ë ë ë ë ë ë ë ë ë ë . ë			
j	Other			
	(if yes,)Specify what kind of action or advice ë ë ë ë ë ë ë ë ë ë ë ë ë ë ë ë ë ë ë . ë			

Thank you for your time

Annexure III: Ethical Clearance Certificate