

ORAL-HEALTH-RELATED QUALITY OF LIFE AND ORAL HEALTH NEEDS OF ADOLESCENTS LIVING WITH HIV IN JOHANNESBURG

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A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg in fulfilment of the requirements for the degree of

Doctor of Philosophy

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DECLARATION

I, Yolanda Malele-Kolisa, declare that this thesis is my own work. It is being submitted for the Degree of Doctor of Philosophy at the University of the Witwatersrand, School of Public Health, Johannesburg. It has not been submitted before for any degree or examination at any other University. I confirm that the work I am submitting for assessment is my own original and independent work excluding where I have explicitly indicated otherwise in the form of acknowledgements or references where appropriate.

Signature: _

Yolanda Malele-Kolisa

April 2021

DEDICATION

This PhD work is dedicated to my three girls, "my loves for life" Kearabetswe, Simntumnye and Bontle without whom the inspiration and stimulation for this PhD would not have come, you were my daily positive Zen.

I would also like to thank my bosom sisters (Phumla and Miranda) and my Dad David Moko for their support. I love you all to infinity.

All my nieces and nephews: Lindiwe, Lehlohonolo, Neo, Thato, Lebohang, Bongani, Rorisang, Boitumelo and Kganya. I thought of you in my writing.

In loving memory of my late mom Nobantu Malele, and late brothers Goodey Malele and Tshepo Malele.

I did it family – we now have a PhD in the family – you were my inspiration and my guardian angels and spirit guides wherever you lay.

To God be the Glory, "I can do all things through Christ who strengthens me – Philippians 4:13 NKJV

PEER REVIEWED PUBLICATIONS AND MANUSCRIPTS ARISING FROM THIS THESIS

Systematic review of factors influencing oral health-related quality of life in children in Africa. Published in African Journal of Primary Health Care Family Medicine. 2019 July 24; 11(1):e1e12.

Understanding the perceptions and experiences of oral conditions and oral health-relatedquality of life among HIV infected and undiagnosed adolescents in Johannesburg, South Africa. Published in South African Dental Journal. June 2019, Vol. 74 No. 5 p223 - p229.

The Burden of Oral Conditions among Adolescents Living With HIV at a Clinic in Johannesburg, South Africa. Published in October 2019, PloS one, 14(10).

Manuscript titled Validation of the modified Child Oral health Impact Profile (COHIP) among HIV infected and HIV-undiagnosed Adolescents in Johannesburg, South Africa. Submitted to BMC Oral Health Jan 2021

CONFERENCE PRESENTATIONS ARISING FROM THIS THESIS

1. Prevalence of Oral-impacts on Daily performance Among HIV-adolescents, Johannesburg, South Africa. Y Kolisa, V Yengopal, Z Joosab. The 48TH Scientific Meeting of the International Association For Dental Research (South African Division).

2. Adolescents' Perceptions, understanding and experiences regarding oral health care, Johannesburg, South Africa: Oral-health-related quality of life factors. Authors: Y Kolisa, J Igumbor, V Yengopal, CB Nqcobo, P Sodo, S Nieuwoudt at the Public Health Association of South Africa, Cape Town 2019.

ABSTRACT

Introduction: The reported high burden of oral diseases among HIV infected adolescents raises concerns about their Oral Health-Related Quality of Life (OHRQoL). OHRQoL is described as the effect of oral conditions on the overall functioning and wellbeing of individuals and it is influenced by shared sociocultural and economic contexts. Consequently, identifying the factors influencing OHRQoL in the African setting is important to inform the provision of responsive oral health services that ensures better wellbeing of adolescents. This proposition is against the fact that the existing OHRQoL assessment tools for children and adolescents have been conceptualised in non-African settings. Consequently, these may not be applicable in an Africa setting given the contextual differences. Additionally, there are inconsistent reports on the prevalence of oral conditions and their associated factors among adolescents living with HIV (ALHIV). The inconsistencies may hinder the development of clear guidelines on the prevention and treatment of oral conditions among ALHIV. This study, therefore, describes the OHRQoL and oral health needs of HIV infected and undiagnosed adolescents in Johannesburg using a contextually appropriate tool.

Methods: The overall PhD study approach was a sequential mixed-method combining both qualitative and quantitative components. The qualitative component was used to generate prevailing perceptions and experiences of OHRQoL. The findings of the qualitative component were used to augment an existing OHRQoL measurement tool developed in a different context. Further, the psychometric properties of the resulting locally appropriate OHRQoL tool was assessed and the adjusted tool was used to measure the oral-health-related quality of life outcomes and their determinants among the study participants using a quantitative research approach.

A part of the quantitative component assessed the prevalence of oral conditions and the impacts of the oral conditions in both groups of the adolescents (consisting of HIV infected and undiagnosed adolescents). Decayed Teeth (DT), Decayed Missing and Filled Teeth (DMFT) and Oral HIV/AIDS Research Alliance (OHARA) case definitions were used for caries examination and reporting of the oral mucosal lesions. The OHRQoL outcomes were measured with our modified Child Oral Health Impact Profile tool.

An epidemiological update of the oral lesions' pattern among ALHIV was done as well using the DT, DMFT and OHARA indices. Data analyses were structured by the study main outcomes; chi-squared tests were performed to determine the associations between variables; and multiple logistic regressions were used to identify associated factors after adjusting for confounding exposure variables. In addition, Cronbach's alpha tests, exploratory and confirmatory analysis were conducted for the validity measurement and the psychometric properties assessment of the modified tool.

Results: Eight themes classified into three levels were identified by the qualitative exploration of the adolescents' perception of OHRQoL. The three levels were at the individual-level, external and social level. The specific eight themes included a) oral health awareness, b) felt oral symptoms, c) impaired oral functioning, d) coping e) access to dental facilities, f) experiences of using health services g) social interaction and h) self-stigmatisation. These themes were appropriately incorporated into the existing Child Oral Health Impact (COHIP) tool modified for the current setting.

From the epidemiological update of oral conditions among ALHIV (n=407) the overall prevalence of dental caries was 56.76% (n=231) with a mean DT score of 2.0 (SD 2.48) and a mean DMFT score of 2.65 (SD 3.01). The prevalence of oral mucosal lesions (OML) was 22%, with linear gingival erythema accounting for most of the lesions at 13.8%.

Dental caries prevalence was significantly associated with the HIV clinical markers (HIV RNA viral loads > 1000 copies/ml; CD4 cell counts less than 200 count cells/mm3 as well as WHO staging III, IV). Among ALHIV, the prevalence of dental caries was directly related to the presence of oral mucosal lesions (p<0.05). Multiple logistic regression modelling showed that dental caries experience (DMFT>0), age category 13-15 years, WHO staging of IV and viral load > than 1000 copies/ml significantly predicted the outcome of oral lesions (p<0.05). The odds of developing dental caries was also 1.5 times more among ALHIV who brush their teeth less frequently and those who reported a sugary diet.

In the comparative phase of the study, a total of 504 adolescents recruited from a HIV Wellness Site (n=226) and School Sites with HIV undiagnosed adolescents (n= 278) were included in the study. The overall mean decayed teeth for permanent dentition was 1.6(SD 1.99) and caries prevalence was 62.2 % (n=309) among all adolescents. The overall M-COHIP score was 59.6(18.2).

The overall modified COHIP scores for those in schools were higher [62.88(1.08)] when compared to that of ALHIV [55.54(1.20)] recruited from the HIV Wellness Site. The poor M-COHIP scores were associated with reporting toothache, having active decay, poor oral health-self-rating, and being selected from the school site, (p<0.005). The main factors influencing OHRQoL followed an existing conceptual framework and were at individual-level: oral mucosal problems, children perceptions and awareness; and at external level including factors such as dental facility access and socioeconomic factors.

Conclusion: The perceptions and experiences of OHRQoL among ALHIV in Johannesburg were influenced by a combination of self-perceptions and social connections, together with the state of their structural environment and biological wellbeing. The participants placed high value on the importance of coping, symptom endurance and dental facility service experiences in determining OHRQoL.

There is high prevalence of dental caries and OML among ALHIV in Johannesburg. The reported prevalence was associated with high HIV RNA viral loads, low CD4 cell count and high WHO staging of HIV disease. Additionally, caries experience contributed to the prevalence of OML. Our study acknowledges the protective effect of HIV treatment and positive oral health practices on the presence of oral conditions among ALHIV in Johannesburg.

The modified oral-health-related quality of life tool displayed acceptable initial reliability and validity. The adolescents' OHRQoL scores were related to the high untreated-caries, toothache reports, poor self-rated oral health and being in schools.

In all, this PhD suggests an association between adolescents' OHRQoL and their individuallevel factors such as perception, oral problems, and environmental determinants (such as socioeconomic and dental facility access factors). More studies may be needed to further assess the new sub-scales among other South African sub-groups particularly the adolescents in rural areas given the urban focus of this PhD. These findings may be relevant in improving oral health services in meeting adolescents' oral health needs.

Keywords: oral health; oral health-related quality of life; factors; children; adolescent, Africa.

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LIST OF ABBREVIATIONS and ACRONYMS

AAS	African Academy of Sciences
AESA	Alliance for Accelerating Excellence in Science in Africa
AIDS	Acquired Immune Deficiency Syndrome
ALHIV	Adolescents Living with HIV
ART	Antiretroviral Treatment
CARTA	Consortium for Advanced Research Training in Africa
CFA	Confirmatory Factor Analysis
CI	Confidence Interval
CINAHL	Cumulative Index of Nursing and Allied Health Literature
СМЈАН	Charlotte Maxeke Johannesburg Academic Hospital
COHIP	Child Oral Health Impact Profile
COHIP-SF	Child Oral Health Impact Profile-Short Form
СОНОР	Community Oral Health Outreach Project
COHQOL	Child Oral Health Quality of Life Questionnaire
COIDP	Child Oral Impacts On Daily Performances
C-S	Cross Sectional Study
DAAD	Deutscher Akademischer Austauschdienst
DMFT	Decayed-Missing-Filled Teeth
DT	Decayed Teeth
EBSCOhost	Elton B. Stephens Co.
ECC	European Clearinghouse Classification
ECOHIS	Early Childhood Oral Health Impact Scale

EFA	Exploratory Factor Analysis
EMBASE	Excerpta Medical Database
ESAR	The Eastern and Southern Africa Region
F	Filled
FDI	Federal Dental Internationale /e World Dental Federation
FIS	Family Impact Scale
GP	Gauteng Province
HIV	Human Immunodeficiency Virus
HIV RNA	HIV Ribonucleic Acid
HPCSA	Health Professions Council of South Africa
HREC	Human Research Ethics Committee
HRQoL	Health Related Quality Of Life
ICF	International Classification of Functioning, Disability and Health
IDIs	In-depth Interviews
IQR	Inter-Quartile Range
ITQOL	Infant Toddler Quality of Life Questionnaire
JBI	Joanna Briggs Institute
КМО	Kaiser-Meyer-Olkin
M	Missing
M-COHIP	Modified Child Oral Health Impact Profile
	Madical Litantum Analysis and Datained Co. (
MEDLINE or MEDLARS	Medical Literature Analysis and Retrieval System Online

NEPAD	New Partnership for Africa's Development Planning and Coordinating
	Agency
NNRTI	Non- Nucleoside Reverse Transcriptase Inhibitors
NOS	Non-specific Ulceration
NRTI	Nucleoside Reverse Transcriptase Inhibitors
OHARA	Oral HIV AIDS Research Alliance
OHRQoL	Oral-Health-Related Quality of Life
OIDP	Oral Impacts on Daily Performances
OML	Oral Mucosal Lesions
OR	Odds Ratio
P-CPQ	Parental/Caregiver Perceptions Questionnaire
PedsQL	Paediatric Quality of Life-Oral Health Scale
PI	Protease Inhibitors
PLHIV	People living with HIV
POQL	Paediatric Oral-Health-Related Quality Of Life
PRISMA	Preferred Reporting items for Systematic Reviews and Meta-Analyses
PROSPERO	International Prospective Register of Systematic Reviews
RCT	Randomised Controlled Trial
SA	South Africa
SADJ	South African Dental Journal
SANAC	South African National Aids Council
SES	Socioeconomic Status
SiC	Significant caries Index

SOC	Sense Of Coherence
SOHO	Scale of Oral Health Outcomes
SSA	Sub-Saharan African
UK	United Kingdom
UNAIDS	United Nations –AIDS
US	United States
USA	United States of America
WHO	World Health Organization
WHO-ICIDH	World Health Organization International Classification of
	Impairments, Disabilities, and Handicaps

CHAPTER 1: INTRODUCTION AND OUTLINE OF THE THESIS 1.1 BACKGROUND

There are 37.9 million people infected with the Human Immunodeficiency Virus (HIV) globally(1). The incidences and manifestations of HIV vary by geographic region and sociodemographic characteristics. In 2018, about 1.6 million of the global adolescent population aged 10-19 were living with HIV infection. In the same year, about 190,000 new infections were recorded worldwide (2). According to the UNICEF 2018 estimates, Sub-Saharan Africa is home to about 90% of HIV infected adolescents (3). South Africa has the highest number of people living with HIV in the world, accounting for almost 310,000 of the global burden of adolescents living with HIV (ALHIV) (4).

Oral diseases such as dental caries, periodontal problems, malocclusion and traumatic dental injuries remain high among the adolescence cohort (5). Consequently, a focus on oral health during the adolescence years is essential. The mentioned oral diseases render oral health as one of the most unmet health care needs of adolescents(6). Aside from the usual and constant issues of caries management, sports injury prevention, and gingival problems, adolescents have specific needs pertaining to oral health. Younger people are also most-at-risk of oral piercings, increased sugar intake, smoking initiation, and malocclusions (7). Therefore, all adolescents generally need a unique approach to motivate them concerning their oral health issues (7). This is particularly important because lifelong health habits are created during these formative years. Additionally, prevention opportunities are effective and can have better uptake at this age (6).

For ALHIV, there has been a remarkable success in the fight against the HIV/AIDS epidemic due, in part, to advances in antiretroviral treatment (ART) and its coverage (8).

However, incidences of HIV among adolescents and young people have not amply decreased to curb the epidemic (9). The effects of the epidemic are evident in the present burden of oral diseases such as dental caries and periodontal problems. These are still experienced by ALHIV and are related to their immunological profile(10). Notwithstanding this, the positive contribution of ART on oral diseases has been shown by a lesser prevalence of oral lesions (11-13).

Despite widespread access to ART, unmet oral health care needs remain a challenge among adolescents (12, 14). HIV infection primarily poses an added risk of acquiring opportunistic oral diseases in non-virally suppressed HIV infected adolescents (15-17). Oral lesions have been used as an adjunct to indicators of HIV infection, predictors of disease progression (18, 19), as well as a sign of poor adherence (20). A review report indicated that dental caries worsened with the deterioration of children's viral loads (10). In addition, dental caries may be related to xerostomia that is induced by the use of ART (21, 22). Poor oral hygiene, social and demographic barriers, periodontal diseases and irregular access to dental services predisposes the adolescents further(12).

The adolescent phase of life has a myriad of life changes besides the added considerations of living with the HIV infection. Thus, managing ALHIV on ART presents additional challenges that may perpetuate the existence of oral lesions. For instance, the oral health of adolescents is influenced by environmental factors such as diet, independence to seek care, compliance to care, low priority for oral hygiene, self-image disturbance and social acceptance (23). The disclosure of HIV status to perinatal HIV infected adolescents may have other mental health implications and effects. This is so, considering that the mean age of disclosure in South Africa stands at about ten years of age (24).

Added to these are other known factors such as treatment fatigue(25) and depression (26) that influence treatment adherence, particularly among adolescents (27). The prevalence of oral lesions among children and adolescents living with HIV vary in different regions. Studies in India inform that up to 60% of patients either had oral mucosal lesions or dental caries (28, 29). Similar observations have been made in Brazil (51%), Mexico (51%), Nigeria (62%), Uganda (68%) and South Africa (71%) (16, 17, 30-32).

Oral diseases prevalence can lead to a lower oral-health-related quality of life (OHRQoL) (33-35). OHRQoL is described as the effects of oral conditions on the daily functioning and wellbeing of an individual (36). Oral diseases can have profound effects on the overall health, which include, among others, pain, missing school, heart disease, and even death(6). The effects of oral conditions on the OHRQoL of HIV infected children and adolescents can be as high as 70% (37-40). High viral loads, non-adherence to ART and low CD4 cell counts have also been associated with poor OHRQoL (37-40). The conceptualisation of oral-health-related quality of life is informed by the context one lives in (41). Hence, despite the translation and adaptation of the tools, children in different geographical regions of the world have responded differently to the social and emotional wellbeing constructs of OHRQoL assessment instruments (42-46). The differences may be explained by the embedded cultural relativism and its subsequent influence (47). The children's sociocultural constructs and nature of symptoms have a bearing on how they conceptualise and perceive health (47, 48). Quality of life, therefore, varies with sociocultural and economic influences and thus, the question arises as to whether this may be the case in the South African context?

Numerous conceptual frameworks in this field examine various pathways of interaction between biomedical and psychosocial dimensions. The basic conceptual framework which guided the research was developed by Ferrens and colleagues (2005), subsequently improved and applied to oral health by Sischo and Broder in 2011(35, 49). This model postulates that the biological-symptom-functional status is influenced by the characteristics of an individual and that of the environment from the outer level, which together influence general health perceptions that determine the status of the OHRQoL. The framework was applied to assess the applicability of the OHRQoL tool in the South African setting; and to hypothesise that OHRQoL among ALHIV are influenced by their socialisation, psyche, resilience, socioeconomic, and biological determinants.

1.2 STUDY RATIONALE

South Africa has the highest number of people living with HIV in the world, as it is home to 7.7 million HIV infected people (3). HIV prevalence among the 15-49 years age group was reported to be at 20.4% in 2019 (2). While the course of HIV prevalence worldwide and in South Africa is promising as the epidemiology is plateauing(4), the infection rate among adolescents remains high. In 2018, South Africa had 38 000 new HIV infections among adolescents between the ages of 10 and 19 years. This is compared to 5 400 in Zimbabwe, 1 600 in Lesotho, and 1 300 in eSwatini. In addition, there were 1 100 in Botswana and less than 1 000 in Namibia in the same year (4). HIV infected adolescents on ART represent an emerging population with improved survival resulting from treatment. However, the chronicity of HIV infection may be presenting a different pattern of oral diseases from what was previously known. This assertion applies to the emergent adolescent population living with HIV(50).

Studies in adult population on long-term ARV treatment have reported the emergence of oral warts (20, 51). The ALHIV carry a significant burden of HIV and the oral disease burden prevalent among those with high viral loads and repressed immune response (52). Patton et al., in 2012 and Arrive' et al., in 2016 described a different pattern of oral disease in young populations linked to adherence to treatment namely, the prevalence of ulcerative gingivitis and candidiasis among those with high viral loads (11, 53). An epidemiological assessment and update of oral health care needs is, therefore, essential to inform the responsiveness and quality of care, and overall oral healthcare planning. This imperative is also given the widespread unmet oral health care needs among people living with HIV (12).

The measurement of OHRQoL in adolescents living with HIV is particularly crucial at this phase as a myriad of life changes, notwithstanding the added requirements of living with HIV infection, significantly impact on their quality of life. This adolescent phase – precarious and fragile – marks the beginning of the development of consciousness that determines character and personality realisation. In the process of developing their own unique social identity, youngsters frequently encounter periods of confusion and uncertainty(7). This exposes them to several adolescent risk factors and, ultimately, new oral health risk factors tend to emerge during adolescence.

Adolescents infected with HIV have been marginally investigated in the broad field of oralhealth-related quality of life. This gap is notably profound in African settings(11). It is, therefore, essential to understand adolescents' oral disease experience and the resultant state of OHRQoL, considering that the adolescent life stage influences their subjective and objective views on their quality of life(48).

The OHRQoL is subjective and influenced by cultural and societal contexts (48). Existing tools to measure OHRQoL directed at the child, have been mostly tested among non-African populations (54-57). Johannesburg is a cosmopolitan urban city with high migrant populations contending with post-apartheid consequences. This scenario presents a unique mix of influences that could further negate prior theoretical assumptions of traditional OHRQoL frameworks and tools.

This situation necessitates a qualitative assessment of the applicability of existing measuring tools to the South African setting, as they may be culturally and contextually inappropriate. When applied to different cultural backgrounds, existing OHRQoL tools showed discrepancies

when probing the concept of ethnicity and socialisation, according to Traebert et al. (2010)(58). Therefore, qualitative research designs have the intrinsic ability to understanding the feelings, and explaining the meaning of data, values and lived experiences of study populations.

Additionally, the OHRQoL patient-reported outcomes have been used to assess the economic burden on individuals and their families(59). The investigation of OHRQoL outcomes necessitates a thorough understanding of the measurement of OHRQoL; with the more significant reason that, according to Broder (2012), OHRQoL assessments can highlight disparities(60). It was found that children with orofacial clefts but without health insurance and from ethnic minorities had a lower OHRQoL(60). Moreover, OHRQoL measures have been used to access oral health needs (34, 61). Oral health needs information is essential for health service planning and public health policy formulation. The proposed study constitutes the initial reference point in the South African setting upon which future studies may assess the trends of patient-reported oral health needs and planning of oral health services for the HIV infected young population.

The findings of this study may unravel precise opportunities to educate and empower adolescents to take control of their oral health in the transition to adulthood. The adolescents' subjective inputs should be included in treatment protocols so that the impacts on their OHRQoL are addressed as part of their overall integrated health care and wellbeing. Often, adolescents have an increased focus on personal aesthetics. This can provide an entry point to discuss oral health knowledge and behaviours during healthcare visits. Indeed, for ALHIV, regular monitoring is required in order to identify their special needs; in this regard, a valid OHRQoL assessment instrument tool will be handy.

Studies in this OHRQoL field, especially among HIV infected adolescents in the African locality and South Africa specifically, are sparse. This study, therefore, sought to ascertain the status quo regarding the pattern and effects of oral conditions among HIV infected adolescents. This exercise also included the assessment of the patient-reported OHRQoL using mixed-methods for a comprehensive exploration of the determinants and sociocultural influences on OHRQoL in HIV infected adolescents in Johannesburg, South Africa. A thorough and accurate understanding of OHRQoL necessitated the in-depth exploration of contextual descriptions and participants' understanding of the meaning of OHRQoL.

Thus, the study explored these concepts and their associated determinants qualitatively and quantitatively.

1.3 AIM

The study aimed to assess oral health needs and the oral-health-related quality of life of HIV infected adolescents in Johannesburg.

1.4 SPECIFIC OBJECTIVES

- a) To conduct a systematic review of factors influencing oral-health-related issues among children in Africa;
- b) To explore the perceptions and experiences of oral conditions and oral health-relatedquality of life among HIV infected and undiagnosed adolescents in Johannesburg, South Africa;
- c) To assess the pattern and burden of oral disease among adolescents living with HIV in Johannesburg;
- d) To determine the validity of a modified oral-health-related quality of life tool (the modified Child Oral Health Impact Profile (COHIP) among South African Adolescents living in Johannesburg; and,
- e) Lastly, to determine the association between oral diseases and OHRQoL among South African adolescents in Johannesburg.

1.5 OUTLINE OF THE DIVIDED BLOCK FORMAT THESIS

This thesis is presented in the divided block format. The following constitute a divided block thesis format, as prescribed by the Faculty of Health Sciences: verbatim "If publications have emanated from the thesis then these publications can be used as the basis for each results chapter. Thus, if one has published all the data from the thesis in four publications, then one would convert these into four results chapters, ensuring that each results chapter has the same format and referencing style. The publications should also be included in an appendix at the end of the thesis." Page 45 Appendix G of the Style Guide of the theses, dissertation and research reports updated in 2016.

The dived block format covers the following chapters:

- A chapter on the literature survey;
- A methods chapter; and,
- The results will be presented in separate, discrete chapters as follows:
 - Each of these chapters is subdivided into introduction, methods, results and discussion sections much like the format used for research publications.
- References can appear at the end of each results chapter in which case only those articles cited in that particular chapter are listed.
- A discussion and conclusion chapter will be added to discuss and synthesise the whole thesis results.

SEE HEREWITH A STRUCTURE OF THE CHAPTERS:

Chapter 1: This chapter presented the introduction with the background of the problem. The study gaps were described leading to the rationale and outlining of the study aim and objectives.

Chapter 2: This chapter is a critique and account of the relevant literature on oral-health-related quality of life and its association with oral diseases among adolescents.

Chapter 3: This chapter describes the methods that were used in the study.

Chapters 4-7: Present the PhD study findings under their published titles:

Chapter 4: Systematic review of factors influencing oral health-related quality of life in children in Africa. Published in Afr J Prim Health Care Fam Med. 2019 Jul 24; 11(1):e1-e12.

Chapter 5: Understanding the perceptions and experiences of oral conditions and oral healthrelated quality of life among HIV infected and undiagnosed adolescents in Johannesburg, South Africa. Published in SADJ June 2019, Vol. 74 No. 5 p223 - p229.

Chapter 6: The Burden of Oral Conditions among Adolescents Living With HIV at a Clinic in Johannesburg, South Africa. Published in October 2019, PloS one, 14(10).

Chapter 7: Prepared manuscript titled: Validation of the modified Child Oral Health Impact Profile (COHIP) among Adolescents in Johannesburg, South Africa; which also discusses the predictors influencing OHRQoL among South African Adolescents in Johannesburg. **Chapter 8:** This chapter provides an assimilated discussion of the overall study as well as the overall study conclusions, recommendations and possible areas for future research.

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CHAPTER 2: LITERATURE REVIEW

2.0 INTRODUCTION

This chapter appraises the body of knowledge and literature in the area of Human Immune deficiency Virus (HIV) infection generally and in South Africa. The idea is to provide a scenario on the prevalence of HIV more so in the time of the study and the HIV burden among the adolescent population. Thereafter, the oral disease epidemiology, the pattern and oral disease trends are described contrasting both the developing and the developed country settings. The adolescence, as a vulnerable phase for health conditions, was discussed and zoned into the oral diseases together with the related contributing factors such as behavioural and socioeconomic influences. The next part of the chapter provides a synopsis of the antiretroviral therapy discourse and the contribution to oral diseases more so in the adolescent population.

The conceptual framework of oral health quality of life is described drawing from the field of health-related quality of life. The conceptual framework by Sischo and Broder is detailed and discussed, framed around all the dimensions of the framework and how it relates to the chosen children's oral health quality of life tool for the study. All patient-reported measurement tools for children and or their caregivers/parents are appraised and their validation status mentioned. The chapter ends with the process of the quality of life measurement tool validation. This step is necessary as the central part of the study is about the applicability of a revised measurement tool in order to fulfil the study outcomes of measuring the oral health quality of life.

2.1 HUMAN IMMUNE DEFICIENCY VIRUS (HIV) INFECTION IN SOUTH AFRICA

The contribution of HIV to global mortality and morbidity and its demands on overstretched healthcare systems in high burden countries make it a public health priority (1). The Eastern and Southern Africa region (ESAR) carries a tremendous burden and is home to about 20.6 million of the world's population living with HIV infection (Fig 2.1). As of 2018, ESAR was also home to more than 60 per cent of children and adolescents living with HIV. Numerically, the adolescents living with HIV infection (ALHIV) in the age range of 10 to 19 years old, constituted about 1.6 million of all people living with HIV. This was topped with 190 000 new infections worldwide in this age range in 2018(2).



Figure 2.1: Adults and children estimated to be living with HIV in 2018

Source: UNAIDS, 2019(1)

Independently, the Sub-Saharan African (SSA) region is home to about 90% of the HIV infected adolescents(3). South Africa carries the highest burden of ALHIV and accounts for about 310 000 of the global burden(4). Approximately 7.7 million or 13% of South Africans are living with HIV infection(4). According to the South African National AIDS Council (SANAC), the country has made considerable strides in achieving the 90-90-90 UNAIDS world targets. These targets are that 90% of the population should be tested for HIV, 90% of HIV positive individuals should be on antiretroviral treatment, and 90% of the people on treatment should be virally suppressed(5). In South Africa, 90% of the population know their HIV status, 68% are on treatment, and 87% are virally suppressed(5).

The antiretroviral treatment (ART) interventions are successful and have increased the life expectancy of South Africans from 56 years in 2010 to 64 years in 2018(6). The National Strategic Plan 2017-2022, recognises young people as a critical population. Therefore, plans are underway not to leave them behind in terms of addressing their needs in order to curb the

scourge of new infections. The Thembisa Model, stated in the UNAIDS 2019 report, brings to attention the slow progress in decreasing the rate of new infections in South Africa. In 2018, there were more than 240 000 new HIV infections. This was a decrease of less than 40% from 2010. In 2017, out of the eight provinces reported, Gauteng was one of the provinces with the lowest prevalence rates at 17.7%. Table 2.1 shows the provinces and districts with the highest HIV prevalence in South Africa. Notably, the districts in Gauteng have an HIV prevalence of 17.7%(7).

Province Prevalence in	District
2017	
1. Kwazulu Natal-27%	eThekwini, Umgungudlovu, Uthungulu, Zululand, Ugu,
	uThukela, Harry Gwala
2. Free State-25.5%	Thabo Mafutsanyane,Lejweleputswa
3. Eastern Cape-25.2%	OR Tambo, Amathole, Alfred Nzo, Chris Hani and Buffalo
	City
4. Mpumalanga-22.8%	Enhlanzeni, Nkangala, Gert Sibande
5. North West-22.7%	Bojanala,Ngaka Modiri Molema,Dr Kenneth Kaunda
6. Gauteng-17.7%	City of Johannensburg, Ekurhuleni, City of Tswane and
	Sedibeng
7. Limpopo-17,2%	Capricon and Mopane
8. Western Cape-12.6%	City of Cape Town

Table 2.1: South African cities with the highest HIV prevalence, 2017

Adapted from the(7) and(8)

Evidence shows that the epidemic is plateauing and stabilising due to the increased prevention, diagnosis and overall management. For instance, the remarkable coverage of maternal HIV prevention care among pregnant and breastfeeding females stood at 93% treatment coverage in 2017(9). The positive outlook of the HIV burden in South Africa led to the reduction of opportunistic infections and mortality due in part to the enhanced immune status from broader access to treatment and care. HIV infection in South Africa is considered and treated as a chronic condition.
Among the gains of the maternal antiretroviral treatment are the improved treatment coverage among women and children, and children with HIV living beyond the adolescent age(10). Antiretroviral treatment is reported to have prevented 1.6 million new HIV infections among children since 2000(11). Consequently, vertically infected youth aged 10 to 19 years old are now emerging as a special population(12). The adolescents infected perinatally and behaviourally have different clinical needs – as shown in Table 2.2 – still, all adolescents need access to care and appropriate support services.

Perinatally infected	Behaviourally infected
More likely to be in advanced stages of HIV	Earlier stages of HIV
More likely to have opportunistic infections	Fewer opportunistic infections
More likely to not be on first-line drugs and	Less likely to need ART and resistance to
in need of complex ART regimens	ART less likely
More obstacles to achieving self-	Less likely to experience obstacles to
management and autonomy	achieving self-management and autonomy
More physical and developmental delays	Less likely to have physical and
	developmental delays
Higher risks of complications during	Lower number of complications during
pregnancy	pregnancy
Higher mortality rates	Long term chronic disease outlook
May not know HIV status although may	May experience more adherence challenges
have been in treatment	
More likely to have experienced multiple	More likely to have denial and fear of HIV
losses related to HIV (parents, siblings, etc.)	
More secrecy regarding disclosure	More likely to be misinformed about HIV
Struggling with issues related to engaging in	May distrust clinical facilities
intimacy, sexuality, and sexual identity	

Table 2.2. ALHIV by transmission routes

May have heightened concerns about	Lack of belief in clinical treatment to
pregnancy and starting families	prevent vertical HIV transmission
More likely to have support from	More likely to lack familial, clinical, and
family/caregiver and health provider	social support

Table verbatim from Sharer and Fullem, 2012 page 2 of the USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1' (12)

The ALHIV and young people in South Africa are most likely to bear a significant burden of the infection despite the growing ART coverage. One in three of the new infections occur among people aged 15 to 25 years old, and the odds of infections are three to five times more likely among females in this age group. Despite the risk, ALHIV today have higher treatment coverage and longer life spans.

Nevertheless, adolescents have additional problems related to transitioning in different aspects of life stages, and their HIV infection status may exacerbate these problems. The added problems include loss of parents and other relatives(13), the onset of puberty(14), disclosure, treatment adherence, HIV stigma issues(15), and negotiating sexual relationships(16). The growing population of adolescents in the region calls for multidisciplinary programmes to address this problem(17) and the burden of oral conditions among children and adolescents with HIV infection.

2.2 ORAL MUCOSAL LESIONS AMONG CHILDREN AND ADOLESCENTS LIVING WITH HIV

The epidemiology of the opportunistic infections such as oral mucosal infections and dental lesions is changing due to improved antiretroviral medication coverage (18, 19).

The following account of the pattern of oral conditions is a summary of studies where children and adolescents living with HIV infection were participants.

In low and middle-income country settings, two Indian studies reported 62%(20) and 64%(21) of oral mucosal lesions prevalence among children and adolescents infected with HIV and some of whom were on ART. No dental caries assessment was performed in Indian studies. In

Brazil, Ribeiro et al. reported 51% oral mucosal lesions and high severity of dental caries with the mean Decayed-Missing-Filled Teeth (DMFT) score of seven among a cohort of 57 children(22). This implies that each child had on average, seven decayed, missing, or filled teeth due to caries. In Mexico, Gaitán-Cepeda et al. reported a 51% prevalence of oral mucosal lesions among about 90 children. No caries data was reported (23). In contrast, a USA study reported low rates of the oral mucosal lesion but high dental caries prevalence rates (61%)) among HIV infected adolescents compared to 50% dental caries prevalence rates among uninfected youths(24, 25).

With regard to African studies, the following prevalence rates were reported: a Nigerian study by Adebola et al. reported 62% prevalence of oral mucosal lesions among 105 children with no dental caries assessment performed(26). In Mali and Senegal, 8.3% prevalence of oral mucosal lesions in addition to 77% dental caries prevalence was recorded among a cohort of 420 children (27). Rwenyonyi et al., in Uganda, reported a 68% prevalence of oral mucosal lesions and 42% dental caries prevalence among 237 children aged 12 years and older (28).

Studies from South Africa reported similar findings. The South African studies were conducted within the HIV wellness centres. Duggal and colleagues conducted a study at a research unit, at Chris Hani-Baragwanath Hospital in Soweto, Johannesburg, on 56 children. Fifty-two per cent of children had oral mucosal lesions. No dental caries assessment was performed (29). In 2012, a study of 277 HIV infected children aged between 4–10 years was conducted at the Johannesburg Hospital to assess the dental caries burden and treatment needs. The dental caries prevalence was 71% with a mean DMFT score of 5 (SD). However, no assessment for the oral mucosal lesions was reported (30). The general trend noted from the referenced studies is that although most children were on ART, the general caries rates were high (29-32), similar to that of the general population. Evidence from the studies from Brazil and Tanzania published between 2006 and 2014 reports the presence of oral mucosal lesions (33-36). According to the WHO report on ART coverage in all age groups, the global coverage was 2 million (7%) in 2005 and increased to 62%- 23.3 million in 2018. However, Brazil had policies on ART since 1996, it was not until 2006 that implementation was realised. In Tanzania, policies on ART roll-out started in 2004, and by 2010 there was a steady increase which resulted in the country recording 66% coverage in 2019 (37).

2.3 ORAL HEALTH NEEDS OF ADOLESCENTS AND THEIR ASSOCIATED FACTORS

The adolescent phase of life involves a transition from childhood to adulthood. This transition is characterised by a myriad of physical, emotional, psychological and human developmental changes. The physical aspect involves physiological and biological changes related to hormonal changes such as body shape/size and voice changes during puberty. Psychological changes include emotional, cognitive and attitude changes, chief among them the development of character, mood swings which are closely linked to social changes such as self-determination and identity, self-care (including oral care) and the roles in society (37, 38).

Health changes and health concerns may also be unique to this phase in life—specifically, oral health which is an integral part of overall health and wellbeing(39). Common oral conditions exhibited by adolescents include periodontal problems, dental caries, poor nutritional habits with oral health implications, dental injuries, malocclusion of teeth and jaws and related aesthetics awareness, dental access problems related to dental phobia, initiation of unhealthy habits such a tobacco and alcohol use, body and tongue piercing and tattooing, eating disorders and many others (40). The oral diseases burden may also be exacerbated by socioeconomic factors such as poor access to dental care (both for preventive and curative purposes) and limited availability of the protective fluoridated toothpaste to protect against sugary medicine (22, 41). Thus, the oral health of an adolescent is essential.

Oral diseases are among the most common unmet health care needs of adolescents (42). Generally, all adolescents need a personalised approach to motivate them about their oral health issues (38). This is particularly important because lifelong health habits are developed during these formative years, and effective prevention opportunities have better uptake at this stage (42).

Adolescents have an increased risk of developing oral conditions due to their biological and environmental contexts. Besides their active lifestyle and adventures of experimentation, they tend to consume drinks with lower pH, thus increasing the likelihood of dental erosion (43, 44). Adding to the list, tooth eruption, development and mixed dentition phase, result in most adolescents generally having a high prevalence of malocclusion problems (38). Other risk factors for oral conditions among adolescents include poor oral hygiene, social and demographic barriers for periodontal diseases (25, 31, 45).

The ALHIV also have added risks of acquiring oral diseases than non-HIV infected children (25, 31). Oral diseases are some of the most common opportunistic diseases in HIV infected children and adolescents (29-31). Oral lesions may be indicators of HIV infection and predictors of progression of the disease (46, 47). In addition, the disclosure of their HIV status to perinatally-HIV infected adolescents may present additional mental health implications and effects as the mean age of disclosure in South Africa is around ten years (48). Thereafter, they have to be counselled about the use of antiretroviral medication and the importance of treatment adherence. Thus, treatment fatigue (49) and depression, just from knowing their HIV status, (50) and treatment adherence are some of the challenges experienced by ALHIV (51). Consequently, poor treatment adherence among ALHIV increases the risk of developing caries, periodontal disease and halitosis (52, 53). Other studies have shown that the use of sugary medicine (syrups) and sugar-sweetened special supplementary diets present additional risks to oral conditions (22, 41). Thus, the resultant risk for oral diseases among ALHIV may be perpetuated and alleviated by factors such as HIV, ART and other biopsychosocial factors described below:

2.3.1 Antiretroviral Therapy and Oral Conditions

Antiretroviral therapy (ART) may affect the prevalence of HIV-related lesions (46). Oral manifestations during the HIV infection may be important markers for immune suppression and virological failure from poor treatment adherence among children on ART (54). Children who are on ART display overall low prevalence of oral lesions. In contrast, those with low CD4 cell counts have more oral lesions (27, 55). HIV infected child populations are more prone to oral diseases (OD) due to their reduced immune response.

Conversely, ART regimen such as the nucleoside reverse transcriptase inhibitors (NRTI), is associated with reduced salivary function and thus, render adolescents prone to dental caries as the protective function of saliva is minimised(52, 53). The xerostomic state is further complicated by the chronic use of sugary syrup medicine and fortified meals prescribed for their routine management of HIV infection and opportunistic infections (22, 41).

Further, whether individually or in combination, ART has specific side effects that affect the oral cavity. For instance, the NRTI has been found to lead to ulcers and xerostomia; the non-nucleoside reverse transcriptase inhibitors (NNRTI) have been associated with erythema multiforme, which can manifest in the oral cavity.

The protease inhibitors (PI) have side effects such as parotid swelling, and a bitter taste, especially in children. This bitter taste might have an impact on treatment adherence (52).

A 2016 study attributed the prevalence of the oral condition to the notion that HIV infection and use of combined ARTs may result in altered oral microorganisms flora (25). The findings were corroborated by a recent 2020 study that found that combined ARVs, specifically the PIs, can change the microbiome in the oral cavity and may alter gingival tissues, rendering individuals at risk of infections and colonisation by dental caries causing bacteria (56). The duration of ART and the different regimens were found to influence the intensity and incidences of oral lesions. The longer the duration, the less the oral mucosal lesions (19, 57).

Another factor related to the reporting of the prevalence of oral lesions in HIV infection are the various diagnostic methods used. This was revealed in a review aimed at providing an update on children and adolescents' oral lesions in HIV/AIDS in low and middle-income countries. Various diagnostic methods may be applied such as the European Clearinghouse Classification (ECC)(19), the Oral HIV/AIDS Research Alliance case definitions (25), also called the modified US Centers for Disease Control and Prevention Classification system. Other studies simply perform a standard soft tissue oral examination and report on their findings (58). These methods have different specificity and sensitivity that may lead to differences in reported prevalence of oral conditions in HIV infected adolescents.

2.3.2 Behavioural Risk Factors for Oral Conditions

The concept of behaviours postulates that all aspects of behaviour are learned and related to the environmental experiences, the stimuli and responses as conceived by psychological theorists (59). Psychological, behavioural scholars state that there are chains of contributing effects between the individual and the environments (60). Individual behaviour is shaped by life situations and the necessary remembered skills or actions as unpacked by the Staats theory of human behaviour (61). Behaviour is learned, thus any condition hampering the learned behaviour, may alter oral health behaviour among adolescent children. There is immediate and long term environmental effect on behaviour.

Children or adolescents' behaviour depend on what has been learned. Existing literature shows oral health behavioural characteristics to be strong predictors of the presence of dental caries and gingival health among adolescents (62, 63).

Dental caries is the most common dental condition in children and more often results in pain and functional limitations (64). It is a disease of lifestyle, affected by social learning and social circumstances and requires good oral health prevention behaviours. For instance, poor oral hygiene and poor dietary habits such as high consumption of sugary drinks and sweets are risk factors for dental caries, particularly among ALHIV (25, 31, 45). The ALHIV may have additional vulnerabilities to oral conditions because they may, due to the perceived compromised status, use nutritional supplements, which are often fortified with sugarsweetened ingredients which predispose them to acquire dental caries (65).

Attitudes refer to the set of belief, emotions and opinions about an object, person or to an object, person, actions or an event. Factors such as experience, social roles and norms, observing or experiencing the situation in the environment influence attitudes and in turn, behaviour. Oral hygiene attitudes are closely associated with behaviours such as regular use of floss, mouth rinsing, and tooth brushing to remove dental plaque (45, 62)which harbours microorganisms responsible for dental caries and gingival conditions. Consequently, good oral hygiene limits the risk of oral diseases (62, 66). Attitudes of adolescents may also be related to delaying health service use until symptoms or complications develop.

Caries prevalence was reported to be inversely related to regular dental access, and good oral health self-rating (67).

2.3.3 Socioeconomic Status (SES) Risk Factors for Oral Diseases

The high burden of oral diseases among ALHIV may also be complicated by their socioeconomic factors such as poor access to and limited availability of dental preventive interventions (22, 41).

Reportedly, parents or guardian occupation and family income influence the presence of dental caries. The higher the household income, the better the oral health outcomes (62). A high household income provides the resources for a healthier diet and greater use of fluoride dentifrices, ultimately leading to improved prevention of dental caries and gingival health (41). Mosciski confirmed the association of healthy non-cariogenic diet and SES in the USA cohorts (25) and Massarente and colleagues in the Brazilian cohorts (31, 63).

2.4 THE CONCEPT OF ORAL-HEALTH-RELATED QUALITY OF LIFE 2.4.1 General Health-Related Quality of Life

Various frameworks and conceptual models in the field of health-related quality of life (HRQoL) seek to improve on existing theories by adding one or more dimensional variables (64). A majority of HRQoL models are based on the biomedical and psychological models. A systematic review of HRQoL models by Bakas et al. (64) revealed the three predominantly used health-related quality of life models. These are the Wilson and Cleary model (1995); (68), the WHO-ICF (2001)(69), and the Ferrans et al. (2005) (70) HRQoL model. Health-related quality of life is a subjective patient-reported outcome, albeit based on objective measurement using validated and reliable tools (71).

Barbosa and Gavião in 2008 found that relationships between biological or clinical variables and HRQoL are not direct. Instead, they are mediated by a variety of personal, social and environmental variables, as well as by the child's development, all of which influence the comprehension about the relationship between health, illness and quality of life (72, 73).

2.4.2 Oral-health-related Quality Of Life (OHRQoL)

The plethora of oral health definitions from numerous scholars has led to many meanings and explanations of OHRQoL (74, 75). There are various schools of thought regarding the 'proper' definitions of oral health.

The World Health Organization (WHO) defines oral health as "a state of being free from chronic mouth and facial pain, oral and throat cancer, oral sores, congenital disabilities such as cleft lip and palate, and gum diseases (76, 77).

The undesirable effects of oral diseases on HIV infected children and adolescents are well documented in literature. The oral diseases result in extreme pain and hamper daily activities (78); may negatively affect average growth; uneven bite causing reduced self-esteem and cognitive development (79, 80); may impair speech, and school performance; and, are costly to manage (18, 81). In a nutshell, that is the 'impact on daily functioning and wellbeing' as summed by Locker and Allen (2007), and thus negatively impact on OHRQoL individuals (75).

The conceptualisation of OHRQoL is context-dependent as it emphasises the relationships on a social sphere. Culture shapes an individual's belief system and influences how health and illness are viewed(82).

2.4.3 HRQoL Conceptual Frameworks

In order to explain and understand the relationships and determinants of HRQoL, the Ferrans et al.(70) model identified individual and environmental characteristics to explain the HRQoL better. The move was an improvement on the relationships in the Wilson and Cleary model of 1995 (68). Ferrans and others (Fig 2.2) proposed that biological-symptom-functional status complex is directly influenced by both individual and environmental characteristics and, in turn, influences overall HRQoL in a unidirectional manner. Sischo and Broder used the Ferrans et al. (70, 83) model in oral health and termed it the 'Theoretical model of OHRQoL'. In so doing, they further unpacked the individual and environmental characteristics (the blue blocks in Fig 2.2). This conceptual framework will be used to understand better the determinants of OHRQoL on two levels – the individual and environmental.



Fig 2.2: A conceptual framework of health-related quality of life and its determinants

Source: Ferrans et al., 2005(70); Sischo and Broder, 2011(83).

Koot and Wallander, report that it is essential to study the determinants of OHRQoL in order to get a better idea of the meaning of OHRQoL in children, their pain and other symptoms and experiences (71). Information on determinants may result in contextual interventions to improve the quality of life. With the above background, this thesis has a systematic review chapter dedicated to exploring if the factors influencing OHRQoL are context-reliant. It has been demonstrated that the increased burden of oral disease in HIV infected children results in a poorer oral health-related quality of life. A majority of recent studies aimed at HIV infected children or adolescents and OHRQoL were conducted in Brazil, in the last ten years. A study by Massarente et al. conducted in 2011, focused on 88 children living with HIV aged 10–15 years. About 93% of these were on ARVs, and the study found the caries burden to be nearly 60%. Socio-demographic, clinical and behavioural factors were linked to poorer OHRQoL (84). A report based on the study of 31 caregivers of children aged 3–6 in 2011, in the same country, recorded lower mean OHRQoL scores (4.13), 65% had caries experience and 24% had herpes stomatitis (34). Still, in 2011, Raymundo and colleagues sampled 59 HIV infected children aged 10–12 years and noted 71% of lesions and low OHRQoL score of 6.09, implying poorer OHRQoL (85).

In Kenya, Masiga and Mimunya also noted negative OHRQoL due to 65% caries levels in their sample of 220 children living with HIV (86) in 2013. A recent report is from Rovaris and co-workers in 2014, using 36 children living with HIV with a mean age of 10 years. This article reported that 82% of children living with HIV were on ARVs, 76% had caries and high-frequency reporting of poor OHRQoL of 69% (36). All Brazilian samples were small, but the bigger Kenyan study corroborated their findings of poore OHRQoL.

It is interesting to note that the era of ARVs does not necessarily result in an improved OHRQoL in children living with HIV. As noted in the Massarente et al. study, while other determining factors play a role, perhaps more studies are required in this field. Research in this area still needs to be strengthened and prioritised, especially in the South African setting.

2.5 CHILDREN'S ORAL-HEALTH-RELATED QUALITY OF LIFE MEASUREMENT TOOLS

The OHRQoL is an outcome that impacts on daily activities of adolescents (75). Measurement of adolescents self-reported OHRQoL is valid, reliable and essential. Self-reported information is vital as it would not otherwise be obtained from proxies.

A synopsis of children's oral-health-related quality of life tools was conducted, and several of these have been identified (Table 2.3). Children specific OHRQoL tools are relevant because oral health perception is subjective and dependent upon children's developmental stages in life.

Measurement tools are, therefore, designed to be able to display differences between diseases and items that are influenced by other non-disease factors should be removed (73).

Ch	ildren OHRQoL	Year	Study	Age group	Validated ;	Development process
То	ol	published	design	participants	internal	
					consistency	
					Cronbach-	
					alpna (σ) score	
1)	FamilyImpactScale(FIS)(87);PARTOFChildOral HealthQualityofLifeQuestionnaire(COHQOL)	2002	CS	Parents	Yes; σ =0.83	Literature review, item generation, item-impact analysis, item relevance, reduction and retention
2)	Parental/Caregiver Perceptions Questionnaire (P- CPQ) (88); PART OF Child Oral Health Quality of Life Questionnaire (COHQOL)	2003	CS	Parents	Yes; σ =0.94	Literature review, item generation, item-impact analysis, item relevance, reduction and retention
3)	Child Perceptions Questionnaire (CPQ ₆₋₇); (CPQ ₈₋₁₀), and (CPQ ₁₁₋₁₄)(89) (90); PART OF Child Oral Health Quality of Life Questionnaire (COHQOL)	2004- 2006	CS	6-7; 8-10; 11-14	Yes; σ=0.89	Literature review, item generation, item-impact analysis, item relevance, reduction and retention
4)	Child Oral Impacts On Daily Performances (COIDP) (91);	2004	CS	11-12 years	Yes; σ =0.71-0.83	Literature review, item reduction and retention
5)	Early Childhood Oral Health Impact Scale (ECOHIS) (92);	2007	CS	3-5 year and families	Yes; σ =0.91-0.95	Item generation based on past Jokovic COHRQoL tool, Literature review and reduction
6)	Child Oral Health Impact Profile(COHIP) (93)	2007	CS	8-15 years	Yes; σ =0.91	Conceptual framework of OHRQoL
7)	Infant Toddler Quality of Life Questionnaire (ITQOL,) (94).	2008	CS	2-months -5 years	Yes; σ =0.84	Review of literature
8)	PedsQL-Oral Health Scale (95)	2009	CS	families	Yes;	Based on general health PedsQL, item reduction and revisions, principal component analysis

 Table 2.3: Synopsis of Children's Oral-Health-Related Quality Life Tools

9) Paediatric Oral- Health-Related Quality Of Life (POQL) (96)	2011	CS	8-14	Yes; σ =0.83-0.86	Lit. review and item generation from existing measure, item reduction, revision
10) Scale of Oral Health Outcomes (SOHO) (97)	2012	CS	5 years and parents	Yes; σ =0.74	Consultative focus group discussions with parents, experts, statistical test for reliability and validity
11) Child Health Utility 9D Index –(98)	2014	CS		Yes; σ =0.87	Generic HRQoL tools that measure QALYs

CS-Cross sectional study design

Many existing OHRQoL measurement tools have different origins. Most were developed from the literature review on items measuring OHRQoL. However, none have been found in the literature that has been developed in the African setting. The online database search revealed that most of the validated tools specific to children's OHRQoL and dentistry were developed in English(89, 96), and translated to Portuguese (99), Spanish (100), KiSwahili-Tanzania(101)), Dutch (102), Thai (103), Chinese(104) and Afrikaans (105) languages among others. Most tools are developed in English speaking countries. Therefore, if they were to be applied to a setting such as South Africa, most would have to be excluded due to language limitations, resulting in systematic bias (106). Translation and adaptation are preferred in order to measure the OHRQoL in a local setting reliably.

2.5.1 The Child Oral Health Impact Profile (COHIP)

The Child Oral Health Impact Profile (COHIP) has a sound theoretical framework, is the first children OHRQoL tool to have both negative and positive impacts, and was developed and validated in a diverse adolescent population. It was for these reasons that it was preferred for this PhD study. The COHIP tool was developed by Broder et al. in 2007 (93) in the United States of America (USA). It was developed to assess the oral-health-related quality of life of children aged 8 to 15 years based on their self-reports. It has 19 items with the following five dimensions: oral health, functional wellbeing, socio-emotional wellbeing, school performance and self-image. This tool was developed with a theoretical basis of OHRQoL by Sischo and Broder in 2011 (83), including biological/genetic factors, psychological, characteristics of the individual, environmental factors. The diversity in terms of ethnicity and oral conditions becomes its strength as it can distinguish differences across diverse populations of adolescents. The COHIP can also measure positive traits or improved wellbeing following intervention (94).

The validity of the scale was excellent after doing inter-group, and intra-group differences. Further, the reliability of the measurement tool was excellent. Construct validity was ensured from performing discriminant and convergent validity assessments. The ability of COHIP tool to distinguish between four patient groups (craniofacial, paediatric, orthodontic and community groups) scores and clinical severity using person correlation, displayed the tool's good discriminant validity. As for the convergent validity, it was measured by association and positive correlation between global self-rating and the COHIP scores.

Based on its transparent and sound theoretical framework, the COHIP tool was used as a loose interview guide in a qualitative inquiry. Hilton and co-authors (107) also used a qualitative enquiry to explore how and what cultural factors affect access to oral health care in different ethnic groups. My adoption of the COHIP was done to identify the layers and levels of the framework relevant for this PhD. The COHIP was also chosen based on its presumption of capturing the positive as opposed to just the adverse effects only like most tools. This resilience factor might be relevant given that the study population were chronic patients at a Wellness Centre where there was full ARTs coverage and, therefore, the expectation of positive health outcomes was more likely.

Before any measurement tool is used for the first time in a context or different type of participants, it ought to be validated and tested for applicability to that context. The validation process is thus described.

2.6 TOOL VALIDATION

Boateng and colleagues report on the best practice and steps for scale development and validity determination(108). These steps are the internal consistency and reliability, tests of construct validity, namely: discriminant as well as concurrent validity, then the exploration of factors, and the confirmation of the factors.

Scale Reliability

Reliability and consistency are often assessed in the early stages of developing a measurement tool that has several items, to confirm and determine if all the items measure a familiar concept and thus, are homogeneous (109). Tavakol and Dennick concur that items that are correlated to each other are homogenous (110). The reliability of an instrument is closely associated with its validity. However, the tool's reliability does not depend on its validity (110).

The test correlations show a level of relationships. According to Salkind (2010), stronger correlations are depicted by the greater coefficients (111) and increase the alpha value (110).

Generally, items that do not correlate well with the scale may be omitted, as they may not be measuring the same construct as the other variables (111). Items may be are added, removed, and modified, according to whether the indices of reliability improve.

The Cronbach's alpha is commonly used to ascertain internal consistency and reliability objectively in a tool. The α -scores for reliability could range from 0 to 1 (110, 111). Meaning, 0.1 to 0.4 (poor); 0.5 to 0.6 (moderate); 0.7 to 0.8 (good); 0.81 to 0.94 (excellent). Very high reliabilities (0.95 or higher) are not necessarily desirable, as this indicates that the items may be entirely redundant (109). It is recommended for a sub-scale to have meaningful internal consistency; it should have at least three or more items or questions (109). Reliability properties are assessed based on context, cultural use and underlying meanings.

Validity

Validity generally relates to the extent to which an instrument measures what it is intended to measure (108, 111). As reported by Streiner and Kottner, validity is not a fixed property of a scale; it differs with every group in different circumstances (112).

Construct Validity: In order for a tool to have sound construct validity, it needs to satisfy both the convergent and the discriminant validity hypotheses. Discriminant validity refers to the tool's ability to discriminate between certain phenomena plausibly. In other words, discriminant validity implies that items that should not be related to each other are in fact, not related (108, 111). A priori hypothesis to satisfy the discriminant validity in this PhD may be: poorer oral health self-rating by participants and the clinical parameter (e.g. pain symptom) should be directly related to the poorer OHRQoL.

Conversely, convergent validity means items that should be related must converge to each other and be related. It is usually appraised by the correlation matrix (112). The goal would be to identify the estimated item's relatedness between the OHRQoL scores and the symptoms, oral diseases or oral health self-rating.

This method uses tests such as the Pearson correlation coefficient. A low correlation may mean that the items may not be well correlated. Streiner and Kottner have suggested a cut off of 0.3 as the minimum correlation for the same construct (112).

Concurrent validity informs us of the extent to which the scores between similar tools correlate with each other. It may also be assessed by between and within-group differences from the overall scores within a measurement tool.

Content and face validity refers to the expert review regarding the extent to which a set of items reflects the content field. These professionals may also assess items for clarity, brevity, grammar and reading level and redundancy, especially with the length of administration in mind (113).

Exploration of Factors

During tool development and validation, exploratory factor analysis (EFA) is applied to assess which items measure the same underlying component. The EFA will delineate a group of items that measure the same dimension. The EFA may also be used to reduce similar items into factors or groups measuring a similar construct. Firstly, items that do not belong to any group and thus do not load anywhere may be considered for removal. The items do not fit if they contribute less than 0.40 to the variation of that factor or redundant if they contribute over 0.80.

Thereafter, subjective and objective thinking is applied at this stage to study items grouped logically and to assign descriptive names to the sub-scale/dimension. The EFA is a fluid and dynamic elimination and revision stage that is used to cluster items (113). Eventually, the initial EFA will lead to tentative dimensions. Worthington and Whittaker suggest that the most rational and logical approach is to conduct EFA then confirm it by Confirmatory Factor Analysis (CFA) (113).

Confirmatory factor analysis is necessary to validate the probable relationships following the EFA. During CFA, the relationships may also be based on the priori theory of relationships.

2.7 CONCLUSION

Despite the widespread coverage and growing access to HIV-related treatment services, unmet oral health care needs are still prevalent in different parts of the world (25). Oral diseases may affect individuals' oral health function, the individual's appearance, discomforts and pain. The above-mentioned risk factors from this review suggest multi-factorial causes of oral conditions and the need for multi-level prevention and treatment interventions. Furthermore, the observations from the literature reviewed signal the need for assessing the oral-health-related quality of life (OHRQoL).

The theoretical framework by Ferrens et al. and Sischo and Broder (70, 83) suggests that OHRQoL is shaped by individual and environmental characteristics functioning in a sociocultural sphere. Hence, context becomes critical in the conceptualisation of OHRQoL. Understanding the adolescents' determinants for both oral diseases amidst HIV infection and the OHRQoL is necessary to guiding and planning relevant and holistic adolescent health programmes.

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CHAPTER 3: METHODS OF THE PhD STUDY

3.1 INTRODUCTION

The overall PhD study approach was a sequential mixed-methods combining both qualitative and quantitative components. The components are described in this chapter and illustrated in Figure 3.1. The qualitative component; Part 1, was used to generate prevailing perceptions and experiences of OHRQoL for benchmarking against global constructs and definitions.

The findings of the qualitative component were used to augment globally recommended OHRQoL constructs, definitions and the measurement tool. Further, the psychometric properties of the resulting locally appropriate OHRQoL tool were assessed, and the modified tool was used to measure the oral-health-related quality of life outcomes and their determinants among the study participants using the quantitative research approach (Fig 3.1 box details). Specifically, Part 1 of the study covered the 1st objective: To explore the perceptions and experiences of oral conditions and oral health-related quality of life among HIV infected and undiagnosed adolescents in Johannesburg, South Africa. The second part of the study addressed objectives 2 to 4 listed below:-

- To assess the pattern and burden of oral disease among adolescents living with HIV in Johannesburg;
- To determine the validity of a modified oral-health-related quality of life tool (the modified Child Oral Health Impact Profile (COHIP) among South African Adolescents living in Johannesburg; and,
- Lastly, to determine the association between oral diseases and OHRQoL among South African adolescents in Johannesburg.



Fig 3.1: The content and structure of the research project

Structurally, Section 3.2 of this chapter discusses the shared general methodological features, while Sections 3.3 to 3.8 focus on the specific study methods and designs of the respective manuscripts that constitute this thesis. Lastly, this chapter ends with a description of the ethical considerations and study limitations.

The PhD study was framed around the oral-health-related quality life framework (Fig 3.2), which posits that individual and external environmental factors impact on the OHRQoL. The study's specific objectives and sub-studies explored the framework in parts and as a whole. The clear blocks in the Figure 3.2 depict aspects of the framework investigated by Objectives 1 to 4.



Fig 3.2: Alignment of PhD study objectives with the conceptual framework of oralhealth-related quality of life and its determinants; Source: Ferrans et al., 2005; Sischo and Broder, 2011 (1, 2).

3.2 GENERAL CROSS-CUTTING METHODOLOGICAL FEATURES

3.2.1 Study Population

The study population comprised adolescents from the Community Oral Health Outreach Project (COHOP) of the University of the Witwatersrand School of Oral Health Sciences. The COHOP has been in existence for about 30 years and serves schools in the inner city of Johannesburg with oral health promotion, prevention, screening and treatment services.

The project's intentions are: to provide primary health care services to the underserved; and, to serve as a platform for teaching and learning among dental undergraduate and postgraduate students in the School of Oral Health Sciences. The services are delivered through the use of two mobile dental trucks with portable equipment.

The project serves the needs of communities that are of low socioeconomic status, and who often experience inadequate access to oral care within the Greater Johannesburg Metropolitan area of Gauteng Province, South Africa (Fig 3.3).



http://ontheworldmap.com/southafrica/city/johannesburg/johannesburglocation-on-the-south-africa-map.html

Source: https://en.wikipedia.org/wiki/Suburbs_of_Johannesburg_

Fig 3.3: Map of Johannesburg

Gauteng Province (GP) is the most populated province in South Africa, housing a quarter (or 15, 2 million) of all South Africa's inhabitants (3). The Greater Johannesburg Metropolitan Area includes areas surrounding the city of Johannesburg where approximately 2,1 million adolescents aged 10 to 19 years old reside. The most common racial group residing in these areas is Black African at 76.5 %. The least is Asian/Indian, forming about 5% of the population. The area is multi-ethnic, and seven per cent of the inhabitants are illiterate (3). The inhabitants of the Greater Johannesburg Metropolitan Area share common identifiers such as socioeconomic status, the average household size of three or less, and the younger population (0-14 years) constitutes about 21 % of its population (3). Twenty-one per cent of the province live with HIV (3).

Participants' Selection

Two groups of adolescents were recruited for comparative purposes. The groups consisted of HIV positive adolescents and HIV undiagnosed adolescents. As a comparator group, the HIV undiagnosed adolescents were recruited from the two schools in the central business district of the Greater Johannesburg Metropolitan community and supported partly by the COHOP programme. The HIV infected adolescents were enrolled from the HIV Wellness site at the Paediatric Virology Clinic within Charlotte Maxeke Johannesburg Academic Hospital (CMJAH). The hospital site is also supported by the School of Oral Health Sciences project. The CMJAH has the catchment population of the Greater Johannesburg Metropolitan Area and the periphery, including the schools selected for this study.

The school participants were part of the schools in the ambit of the Community Oral Health Outreach Project (COHOP) of the University of the Witwatersrand School of Oral Health Sciences. The COHOP serves schools in the inner city of Johannesburg with oral health promotion, prevention, screening and treatment services. The historical trajectory of the inner school evolved in post-apartheid South Africa. Amidst all positive policies and environment after segregation in SA, the education system progressed from the racial division to class divisions (4). With the deterioration of the inner city and the urban decay, came the perception of the regression of the public and private schools in the inner city. The low socioeconomic societies became popular residents, and several private schools mushroomed and were located from the conversion and repurposing of the inner city buildings (4).

The project serves the needs of communities that are of low socioeconomic status, and who often experience inadequate access to oral care within the Greater Johannesburg Metropolitan area. Three schools in the inner city (One private –Nazareth House and two public-Yeoville Boys and combined school) and one in the northern informal settlements of Johannesburg, Diepsloot (Muzimuhle School), are serviced by the COHOP project. The project's intentions are: to provide primary health care services to the underserved; and, to serve as a platform for teaching and learning among dental undergraduate and postgraduate students in the School of Oral Health Sciences. The services are delivered through the use of two mobile dental trucks with portable equipment.

After the research project's approval from the Human Research Ethics Committee (HREC) (Ref. number: M161142) of the Witwatersrand University, a visit was made to the schools to meet the school principals (Appendix 6). The HREC approval was granted after the facilities and schools together with the District's Basic Education Office granted permission to research the facility. The school principals from the inner city schools, upon receipt of the HREC approval and explanation about the study, gave the learners in Grades 7 to 11 parental consent letters to take home for the parents to approve their participation in the study. The learners that came back with the parental consent forms were later asked for their assent (Appendix 1 and 2) to be part of the study interviews and the oral health examination.

Consequently, the study participant list was compiled. During the months of data collection, researchers made an appointment with the teachers to access learners from the list during the allowed time in school. A room was assigned by the school where data collection occurred following the WHO guidelines on oral basic survey methods(5). The information was evident in the parental consent forms and the learners' assent forms that they would be interviewed alone at school. No harm was done, and they were at liberty to discontinue being part of the research at any time without prejudice. The in-depth-interviews were conducted first by two interviewers who are duly qualified dental practitioners. Qualified standardised examiners duly registered with the Health Professions Council of South Africa (HPCSA) in the privacy of the consulting rooms performed the clinical examination.

All children requiring further treatment from both sites were treated immediately, if urgent, or otherwise issued with followed-up appointments for further management.

The methods of selecting individual participants varied depending on the research question and study objectives. The methods are discussed briefly in Sections 3.4 to 3.8. The methods' detailed descriptions are presented in the respective chapters of the thesis. Table 3.1 provides the sampling method, sample sizes and other design and methodological considerations.

The measurement tool for oral-health-related quality of life

The Child Oral Health Impact Profile (COHIP) was selected because it has a sound theoretical framework, is the first children OHRQoL tool to have both negative and positive impacts, and was developed and validated in a diverse adolescent population. The COHIP tool was developed by Broder et al. in 2007 (6) in the United States of America (USA). It was developed to assess the oral-health-related quality of life of the children aged 8 to 15 years based on their self-reports. It has 19 items with the following five dimensions: *oral health, functional wellbeing, socio-emotional wellbeing, school performance and self-image.* This tool was developed with a theoretical basis of OHRQoL by Sischo and Broder in 2011 (2), including biological/genetic factors, psychological characteristics of the individual, and environmental factors. The diversity in terms of ethnicity and oral conditions becomes its strength as it can distinguish differences across diverse populations of adolescents. The COHIP can also measure positive traits or improved wellbeing following intervention (7).

The tool was modified after the steps highlighted in the later chapters of the study project and items were increased from 19 to 29 items and incorporated the new sub-scales or dimensions, i.e.: *dental access, dental facility experiences, and coping*. The last question on oral health self-rating facilitated the discriminant validity measurement. The positive correlation between M-COHIP and the single item on oral self-rating, also referred to as global health rating, measured discriminant validity (Appendix 10). The questionnaire was disseminated in the form of an interview, and the following were the responses required from the participants: *never; almost never; sometimes; fairly often; all the time* had the event occurred in the past three months, attributed to one of the 29 items. The self-rated oral health expected from the question "how would you rate the health of your teeth/mouth in the past three months" response ranged from *poor; fair; average; good and excellent*

The validity of the scale was good after doing inter-group, and intra-group differences and the reliability of the measurement tool was excellent. Construct validity was ensured from performing discriminant and convergent validity assessments. The ability of COHIP tool to distinguish between four patient groups (craniofacial, paediatric, orthodontic and community groups) scores and clinical severity using person correlation, displayed the tool's good discriminant validity. Convergent validity was measured by association and positive correlation between global self-rating and the COHIP scores.

Based on its transparent and sound theoretical framework, the COHIP tool was earlier used as a loose interview guide in a qualitative inquiry. Hilton and co-authors (8) also used a qualitative enquiry to explore how and what cultural factors affect access to oral health care in different ethnic groups. The adoption of the COHIP was done to identify the layers and levels of the framework relevant for this PhD. The COHIP was also chosen based on its presumption of capturing the positive as opposed to just the adverse effects only like most tools. This resilience factor might be relevant given that the study population were chronic patients at a Wellness Centre where there was full ARTs coverage and, therefore, the expectation of positive health outcomes was more likely.

Study objective:	1. To conduct a systematic review of factors influencing oral-health-related quality of life among children in Africa.	2. To explore the perceptions and experiences regarding oral conditions and oral health- related-quality of life among HIV infected and undiagnosed adolescents in Johannesburg, South Africa	3. To assess the pattern and burden of oral disease among adolescents living with HIV in Johannesburg.	4. To assess validity of a modified oral health- related- quality of life tool (the modified Child Oral health Impact Profile (M- COHIP) among South African Adolescents.	5. To determine the predictors influencing OHRQoL among South African Adolescents in Johannesburg
Study	*Children in Africa	Adolescents in	Adolescents in	Adolescents in	Adolescents in
Population		Johannesburg Sites	Johannesburg Sites	Johannesburg Sites	Johannesburg Sites
		(Hospital and School)	(Hospital only)	(Hospital and School)	(Hospital and School)
Sampling	Purposive	Purposive	Recruitment at clinical site based on eligibility	Recruitment at clinical site based on eligibility and random selection for comparator	Recruitment at clinical site based on eligibility and random selection for comparator
Design	Systematic review	Qualitative exploratory	Cross sectional	Comparative cross sectional	Comparative cross sectional
Size	Final ten papers were included	25	407	502	502
Key variables	Factors influencing	In-depth Interviews of boys	Socio-demographic	Socio-demographic	Socio-demographic
measured	OHRQoL among children in Africa	and girls aged 14–19 years	variables; CD4 count; viral loads; duration on ART etc. dental caries prevalence; oral mucosal lesions; oral health behaviour	variables; dental caries prevalence; oral mucosal lesions; oral health self-rating with OHRQoL scores	variables; dental caries prevalence; oral health self-rating with OHRQoL scores
Data collection	Systematic online database search	In-depth Interviews	Clinical examination (DMFT & OHARA)	Clinical examination (DMFT & OHARA)	Clinical examination Questionnaire – modified C-OHIP

Table3.1: Summary of study design and methodology by objective.

				Questionnaire – modified C-OHIP	
Data Analysis	Meta-analysis	Thematic content analysis	Descriptive statistics Intra/inter-examiner reliability-kappa score Bivariate analysis Multivariate logistic regression model	Descriptive statistics Cronbach-alpha, exploratory & confirmatory factor analysis, Chi-squared tests and Bonferroni tests	Descriptive statistics Chi-squared tests and Bonferroni tests

*The inclusion criteria of the articles in the systematic review were articles with children or reports on children by parents. According to the World Health Organization: "A child is a person 19 years or younger and adolescent are those children aged 10 to 19 years; therefore, children include adolescents.

Quantitative data analysis

Table 3.1 shows the analysis approach per the objectives of the study. For the quantitative approach, the independent or exposure variables were age, sex, and socioeconomic variable using the proxy of the parents' employment status. Behavioural traits such as tooth brushing habits, and sweets and sweetened beverages consumption, including the adolescents rating of oral health, was collected for both objectives 3 and 4. The self-rated oral health variable was used for the global health rating. This denotes a general question on the individuals' view about their health, from their perspective. Latham and colleagues report that this question is usually responded to on a Likert scale as "excellent, very good, good, fair, or poor". In surveys, it is deliberately vague in assessing different dimensions of health. The self-rated health question shown forecasts morbidity (1).

The dependant variable was the oral disease status using the decayed component and the decayed, missing a filled component, and oral mucosal lesions case definitions by Oral HIV/AIDS Research alliance. Also, oral health relied upon the quality of life scores. The continuous variables were assessed for normality spread by applying skewness and kurtosis tests using the stats commands 'sktest and swilk' in Stata statistical package. Outcome variables were also dichotomised for chi-squared analysis for normally distributed data into "D=0 &D>0; DMFT=0 & DMFT>0; OHARA=0 & OHARA>0".

Qualitative Data Analysis

Qualitative data analysis followed a thematic content analysis. Trustworthiness in qualitative research is ensured through satisfying the following criteria: credibility, dependability, confirmability, and transferability (2).

Credibility refers to how accurate the data are or participants' reports and views as represented by the researcher/s (2). In this study, the credibility was enriched by the researchers through independently coding and analysing the data (by three coders), and reported the participants' experiences, verified the information by member checking, that is, confirming with the adolescents the analysed information as they described it. Once off member checking with the few adolescents was done to ascertain whether their views had been adequately described. Peer and supervisors' scrutiny and member checking were added measures to ensure credibility.

Dependability denotes the reliability of the data over similar conditions in different study sites. The two study sites with a similar background of adolescents yielded the same themes. However, dependability refers to the repeatability of the study by different researchers. To enhance the study's repeatability, the description of the data collection was explained in detail with the posed questions described in the interview guide to ensure dependability.

Confirmability refers to describing how the report, conclusions and interpretations were reached. The transparent method of thematic content analysis explained the process from the data corpus stage, the studying of raw interviews, verbatim transcriptions, independent coding and citing rich text or quotes to support the sub-theme and themes coded.

Transferability refers to the findings that can be realistic and relatable to other settings or groups(2). The study's qualitative phase has achieved this if the results have the same meaning and are relatable to other individuals not in the study or the readers can associate the results with their own experiences.

3.3 SPECIFIC METHODOLOGICAL APPROACH BY STUDY OBJECTIVE

This section presents summaries of methodological approaches applied to the different objectives. These approaches are also shown in Table 3.1.

3.4 Paper 1, Objective 1: To conduct a systematic review of factors influencing the oralhealth-related quality of life among children in Africa.

Below is the summary of the methods used for Objective 1 and, the first peer-review publication. More details are provided in Chapter 4.

3.4.1 Study Design

This was a systematic review; the search strategy included seven databases, no publication date limit was added; the population was, however, limited to children and mothers/caregivers reporting on children; the setting was Africa and, the outcome of interest was factors influencing OHRQoL measured using validated OHRQoL tools.

3.4.2 Sampling

Initially, 337 records were identified. After screening and eligibility processes were performed through the Joana Briggs Institute critical appraisal tools (Appendix 7a-d), the review included ten studies.

3.4.3 Data Extraction Sheet

I developed a data extraction sheet (Appendix 8) for use by all independent reviewers based on the review objective. The sheet contains data on the following: Authors of the article, the title, the publication date, the study design, the sample size included in the study, the study participants, the intervention, the conceptual framework /model specified if any in the article. In addition, the outcome of the study, i.e. the OHRQoL measurement verdict based on the clinical indicator used including the tool used, and lastly the determinants for OHRQoL highlighted in the study formed part of the data extraction sheet.

3.4.4 Data Collection Synthesis and Analysis

Three independent reviewers extracted and appraised the data. The flow of process was described using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart (PRISMA) in Chapter 4. Meta-analysis was done and the results were displayed in forest plots.

3.5 Paper 2, Objective 2: To explore the perceptions and experiences regarding oral conditions and oral health-related quality of life among HIV infected and undiagnosed adolescents in Johannesburg, South Africa.

Below is the summary of the methods used for Objective 2 and, the second peer-reviewed publication. More details are provided in Chapter 5.

3.5.1 Study Population

The adolescent participants were purposively selected from the HIV Wellness site at the Paediatric Virology Clinic within Charlotte Maxeke Johannesburg Academic Hospital (CMJAH), as well as the public schools in the Greater Johannesburg Metropolitan area for the HIV undiagnosed participants. Purposive sampling is a non-random procedure where a researcher sets out to find deliberate participants that can provide the answers as per the researcher's question. This was the preferred technique for finding answers to the question for this study (3).

3.5.2 Sampling

Twenty-five female and male adolescents aged 14 to 19 years were purposively selected in both sites.

3.5.3 Data Collection, Capturing and Data Management

Proper, informed participant assent and parental consent were acquired following regular ethical procedures. The in-depth interviews (IDIs) were conducted in a private room on an agreed-upon appointment day. In-depth interviews were equivalent to personal accounts, and, they are essential when personal viewpoints are imperative in understanding the phenomena being investigated. The IDIs can provide an undiluted focus on the individual. They are a preferred method of collecting data when the researcher is interested in understanding the participants' context, social world, viewpoints, experiences and circumstances (4). They were preferred for this study as opposed to focus group discussions (FGDs). The FGDs present a setting where participants influence one another and, therefore, are useful only where group dynamics highlight the research issues (4). Besides, the adolescents would not have been open to talking about their infirmities and matters bordering on their privacy among one other.

Adolescents were asked about their perceptions of oral conditions and how they affect their daily activities. Using a structured interview guide (Appendix 9), adolescents were also asked about the related experiences with using any dental facility. Independent data coders synthesised the transcripts from the audio-tapes using thematic content analysis.

3.5.4 Data Analysis

Thematic content analysis was applied to analyse the data corpus from the interviews. It involved systematic coding and sorting approach used for exploring large amounts of written verbatim information to create a codebook. The following data analysis steps were used (5).

Familiarisation with data: This involved an initial listening to the audio and reading the transcripts.

Generating initial codes: This step involved generating a codebook by the principal investigator, and coding the interesting features systematically for the whole data set.
This was the initial level of making inferences regarding the meaning of codes in order to create definitions.

Searching for themes among codes: Identified codes were combined into sub-themes and, overall themes were created. A mind map to visualise the data was helpful for this process. To enhance the trustworthiness of the analysis, more than one researcher coded the transcripts independently, and notes were subsequently compared.

Reviewing themes: at this level, the 'working' themes were reviewed and assessed by a second set of reviewers – not part of the initial team – against the theoretical framework. Themes were discussed, separated, deleted and merged at this stage. This step was iterative, revisiting previous steps to seek coherence.

Defining and naming themes: At this stage, it was evident what codes or sub-themes would lead to specific themes. Definitions of themes were outlined, and overarching names were given to these themes.

Producing the final report: a written account of events was done. Once off member checking with the few adolescents was done to ascertain whether their views had been adequately captured.

Throughout the data collection and analysis process, reflexivity was ensured by bracketing. To ensure this point, the investigators made an effort to declare their views and beliefs upfront. The aim was to ensure that findings of interviewees were presented well from their viewpoints and not of the interviewers. Peer and supervisors' scrutiny and member checking were added measures to ensure credibility.

3.6 Paper 3, Objective 3: to assess the pattern and burden of oral disease among adolescents living with HIV in Johannesburg

Below is the summary of the methods used for Objective 3 and, the third peer-reviewed publication. More details are provided in Chapter 6.

3.6.1 Study Population

These were the adolescent users of the HIV Wellness unit at the CMJAH only instead of both groups. The comparator group was not diagnosed with HIV infection.

3.6.2 Sampling

Sample size with more than 85% power was calculated by assuming that 25% of participants with HIV would have controlled viral loads and that 15% of them may have had oral lesions. The sampling approach was based on the premise described in Naing and colleagues (6) for cross-sectional studies. Thereafter, a cross-sectional study comprising 407 adolescent participants was conducted.

3.6.3 Data Collection and Data Management

A clinical examination for both the soft mucosal tissue (OHARA) and the hard dental tissue (DMFT) was conducted following examiner calibration with using the Decayed-Missing-Filled Teeth index (Appendix 3), and the Oral Health AIDS Research Alliance case definitions (Appendix 4) to detect oral conditions' prevalence. Information from the data capture sheets was captured in Microsoft Excel, cleaned and exported into Stata version 14.1. Prevalence of oral conditions was dichotomised into DMFT=0 and DMFT>0, as well as that of presence or absence of soft tissue oral lesions.

Following descriptive and inferential statistical analysis, the predictors of oral conditions were identified by applying the multiple logistic regression analysis. Details of the analysis conducted can be found Chapter 6.

3.7 Paper 4, Objective 4a: to assess the validity of a modified oral-health-related quality of life tool (the modified Child Oral Health Impact Profile (COHIP) among South African adolescents

Below is the summary of the methods used for Objective 4 and the draft manuscript for publication. More details are presented in Chapter 7. The fourth objective has two parts. The first part describes the validity of the modified COHIP, and the second part identifies the predictors of OHRQoL among South African Adolescents in Johannesburg.

3.7.1 Study Population

The adolescent participants from the HIV Wellness site at the Paediatric Virology Clinic within Charlotte Maxeke Johannesburg Academic Hospital (CMJAH), as well as selected public schools in the Greater Johannesburg Metropolitan area for the HIV undiagnosed participants, were included in addressing this objective.

3.7.2 Sampling

The survey consisted of 502 adolescents from two site types (the wellness centre and the schools, respectively). The sample size was calculated by assuming the error margin of 5%, with a 95% confidence interval with 400 adolescent learners. Study sample size calculation suggested 280 randomly selected school learners as a comparator group. The ALHIV group (226) was recruited from the HIV Wellness centre in the Academic hospital following proper, informed consent and assent for both groups.

Those in the schools were excluded if they reported having a chronic medical condition or being on any chronic medication. For the school participants, random computer-generated numbers were used to select adolescents from class lists as a sampling frame to attain the calculated sample size.

3.7.3 Clinical Data Collection Tools

Both Appendix 1 and 2 (Ethical permissions) together with Appendix 3 and 4 (Clinical examinations) were used.

A new, modified oral-health-related quality of life questionnaire was administered to the participants via an interview.

3.7.3.1 Development of data collection questionnaire used in the study

Context is essential in the conceptualisation of oral-health-related quality of life. To assess the accurate reflection of OHRQoL in the South African context, we require socially and culturally sensitive tools which can overcome measurement bias related to ethnicity and context (7). It is for this reason that a specifically modified tool was used to collect data. Instead of applying the original tool developed in the United States of America (8) as it is, the tool was modified to suit the South African context.

The current PhD study first conducted a qualitative inquiry to explore the experiences and perceptions of adolescents with regard to oral conditions and how these might affect their daily activities. The qualitative exploration resulted in more themes arising beyond the five

dimensions of the COHIP tool (Oral Health, Self-Image, School Performance, Socio-Emotional Wellbeing, and Functional Wellbeing) in Fig 3.4 (9).

Through a thorough iterative process, the emerging three dimensions were added to the existing original tool, resulting in eight dimensions used to measure OHRQoL in objective four including the original five dimensions (Oral Health, Self-Image, School Performance, Socio-Emotional Wellbeing, Functional Wellbeing), and the emerging three dimensions (Dental Access, Dental care Experience and Coping).

The original COHIP was, therefore, assessed for conceptual equivalence with the findings of Paper 2, modified and appropriately applied in Paper 4 (detailed in Chapter 7).

Conceptual equivalence - explores the presence of the same meanings in domains, and establishes beliefs and behaviours regarding OHRQoL (10). Domain and items from this target population (SA) may vary from the source COHIP questionnaire. Conceptual equivalence is also assessed by looking at the meanings across cultures to achieve a "similar effect" on participants in Johannesburg's diverse setting (10). There are four possible outcomes of the conceptual equivalence assessment, and they include:

- 1. Domains in the source (original) and target (SA) themes are equally relevant: which then implies using the original questionnaire to assess OHRQoL.
- 2. Domains in the source (original) and target (SA) are the same, but one culture places more importance of one domain over the other. For example, source culture gives more weight on functional symptoms while target culture regards emotional or social domain as more important: in this case, weighting may be warranted.
- 3. One or more domains in the source culture are not relevant in the target culture; target culture has new domains: therefore, relevant domains from the original or source culture might be used or retained with appropriate psychometric testing.
- Different domains are experienced in both source and target cultures: what it means, therefore, is that the COHIP questionnaire should not be used for this population. Instead, a different tool ought to be sought.

3.7.4 Data Management and Data Analysis

Information from questionnaire and data capture sheets were captured in Microsoft Excel, cleaned and exported into Stata version 14.1. Internal consistency of the tool was measured with Cronbach-alpha tests. The tool was analysed for construct validity, concurrent validity, discriminant validity and factors were explored and confirmed with exploratory and confirmatory factor analysis. The tool validation process followed the description in the Literature Review (Chapter 2, section 2.6). The statistical tests used in the tool validation were also summarised in Table 3.1, and further details are provided in Chapter 7.

3.8 Paper 4. Objective 4b: to determine the predictors influencing OHRQoL among South African adolescents in Johannesburg

The following is a summary of the design and methods followed to generate additional information on the predictors influencing OHRQoL among South African Adolescents in Johannesburg. Details of the methodology are presented in Chapter 7. Sampling and data collection tools were the same as those used Objective 4a described above, and the additional analysis on the predictors of OHRQoL is presented here.

3.8.1 Data Analysis Approach

Additional analytic tests were aimed at assessing the predictors of oral-health-related quality of life. The following tests were applied; descriptive statistics, Chi-squared tests, t-tests and regression analysis (Table 3.1). Logistic regression analysis was preferred as it is best fitted to explaining the relationship between binary outcomes and the presence of any type of predictor variable, either nominal, ordinal and categorical. Logistic regression analysis was therefore used to identify relevant predictor variables as well as the direction of the relationship between variables (11).

3.9 ETHICAL CONSIDERATIONS

The ethical aspects of involving children in research are precise and have the best interest of children at all times. The study took to heart the following considerations for conducting research, particularly among minors.

The best interest of a child: Guidelines for researching adolescents are overt and were followed in this study. The aim of the current study was primarily focused on the adolescents' perceptions and experiences of oral health, which would not otherwise be obtained from parents. This knowledge is relevant to meeting the health needs of adolescents. Proper permissions were sought in the form of assent from the minor participants and the parental consent (Appendix 1 and 2).

Rights of a child: Children have a right to equality, privacy, human dignity, safety and freedom of expression. The research followed the four principles of ethics and ensured that the rights of a child were adhered to. The dignity of and respect for children were afforded at all times. Trained interviewers with dental speciality and dental therapist training unobtrusively collected data, with sensitivity, ensuring anonymity and confidentiality in a private room.

Informed consent: The rights of a child are essential, and their permission to be participants in this research is equally important. All children considered for participation in a research project have a right to full information about a research project. All adolescents aged 10–17 years provided assent for being participants (Appendix 1) in addition to parental consent (Appendix 2). Adolescents aged 18–19 years did not require parental consent; they provided their consent.

Voluntary participation: Children's voluntary involvement was maximised. A difference in power relations between the interviewers and the adolescents was resolved by ensuring that recruitment to the study was done after routine treatment had been provided; to reduce the feeling of coercion. In addition, the health personnel not involved in the study, recruited the participants in the presence of their parent/guardian to avoid influence from the presence of the researchers. Literature reports that younger adolescents may not be enrolled if older ones can just be as suitable. Adolescents aged 14–19 years were invited for in-depth interviews, leaving out the 10–13-year-olds (12).

Qualified standardised examiners duly registered with the Health Professions Council of South Africa (HPCSA), in the privacy of the consulting rooms, performed the clinical examination. All children requiring further treatment from both sites were treated immediately, if urgent, or otherwise issued with followed-up appointments for further management.

This study received ethical clearance [Ref. Number: M161142] from the Human Research Ethics Committee of the University of the Witwatersrand, Johannesburg (Appendix 6).

3.10 STUDY LIMITATIONS

The cross-sectional study design is generally a hypothesis-generating study analytically describing the status quo of a phenomenon. They cannot determine casualty. Papers 3 and 4 describe the burden of oral conditions and oral-health-related quality of life using the design. Therefore, a once-off oral examination was done, and the conditions diagnosed may have been acute or recurrent. However, the DMFT scores provided an insight into oral health history and pattern of health services utilisation.

The further rigorous analysis was conducted using logistic regression analysis to determine associations while adjusting for confounders. The reports about the current study should take into cognizance that there was a time lag of about three weeks between the oral examination with the diagnosis of the oral conditions, and HIV clinical markers recorded on the participants' records. However, this lag is not uncommon, as seen in other published reports (13, 14).

Self-reported behaviour in this mixed-methods design may be prone to social desirability. To overcome that, it was prudent to ensure that the analytic process for the qualitative data was credible and trustworthy, by triangulating the information with cross-checking and verifying with the participants. For the validation paper, there may have been social desirability bias from the interviewer-administered questionnaire. However, to reduce the risk of this short-coming, the interviews were conducted comfortably, were relaxed, created rapport and trust, and allayed fears, and the questions were phrased in such a manner as to generate truthful responses. The participants were reassured that there were no wrong answers. The combination of the study participants, and the data collection and analysis methods provided further objective and subjective opportunities to confirm the responses.

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CHAPTER 4 : SYSTEMATIC REVIEW OF FACTORS INFLUENCING ORAL HEALTH-RELATED QUALITY OF LIFE IN CHILDREN IN AFRICA

Title of	Systematic review of factors influencing oral health-related quality					
publication	of life in children in Africa					
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Formal analysis	Yolanda Malele-Kolisa,					
Investigations	Yolanda Malele-Kolisa ,Cathrine B. Nqcobo, Tshakane R.D. Ralephenya					
Data curation	Yolanda Malele-Kolisa ,Cathrine B. Nqcobo, Tshakane R.D.					
	Ralephenya					
Writing – original draft;	Yolanda Malele-Kolisa					
Writing-review	Yolanda Malele-Kolisa, Veerasamy Yengopal, Jude Igumbor,					
and editing;						
Visualization;	Yolanda Malele-Kolisa Cathrine B. Nqcobo,					
Supervision;	Yengopal, Jude Igumbor,					
Project	Yolanda Malele-Kolisa					
administration						

This chapter was the first conceived idea and the first published paper in the PhD milestone. The first fact-finding information on the field necessitated interrogation of the literature on the oral-health-related quality of life among children and the determinants thereof. I was interested in the existing factors that influence oral-health-related quality of life in the African regions. Especially on the conceptualisation of OHRQoL, the contextual and cultural shaping of the concept. The question of who, when and where were the patient-reported OHRQoL children tools developed? What are the predictors or the contributing factors of children's OHRQoL? Searching in this field did not yield coherence information on the combined factors. A systematic review process on the factors or determinants on oral-health-related quality of life among children in was a necessary step to coalesce for my choice of study setting; Johannesburg, South Africa.

Abstract

Background: Oral health-related quality of life (OHRQoL) is influenced by cultural and societal context. Existing OHRQoL children measurement tools have been conceptualised in high income countries. Probing whether the factors influencing OHRQoL are context-reliant in the African setting is necessary and is the purpose of the current review.

Aim: To investigate if the factors influencing OHRQoL are context-reliant.

Methods: Seven databases were searched using search terms ('oral health'; and 'quality of life', 'health-related quality of life', 'patient-reported outcomes', 'wellbeing'; and 'child*', 'adolescents', 'teen*', 'youth'; and 'determinants', 'factors', 'predictors'; and 'oral health quality of life tools/instruments/scales'; and 'Africa*'). Abstracts identified were exported to a reference software manager. Three of the authors used specific selection criteria to review, firstly, 307 abstracts and, secondly, 30 full papers. Data were extracted from these papers using a pre-designed data extraction form, after which quantitative synthesis of data was performed.

Results: Key factors influencing OHRQoL followed an existing conceptual framework where environmental and individual factors in the form of socioeconomic status (SES), area of residence and children psyche status, and the presence of any oral condition other than dental caries were reported among child populations in Africa.

Conclusion: There is preliminary evidence to suggest an association between individual factors such as children's psyche and oral problems, excluding dental caries, and environmental determinants such as area of residence and SES in children's OHRQoL in African children. The finding that dental caries was not a key factor in child oral health is unexpected. There seemed to be a contextual viewpoint underpinning the current OHRQoL frameworks and OHRQoL was context-reliant.

Keywords: oral health; oral health-related quality of life; factors; children; Africa.

4.1 INTRODUCTION

The FDI World Dental Federation vision 2020 defines oral health as: a multi-faceted and includes the ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence and without pain, discomfort and disease of the craniofacial complex (15).

The definition connects with Locker and Allen's concept of oral health-related quality of life (OHRQoL), which is explained simply and loosely as 'impact of oral conditions on daily functioning and wellbeing' (16). Oral health-related quality of life deals with effects and symptoms that vary in intensity and importance. 'Some maybe life threatening (e.g. oral cancers), some chronic (caries, periodontitis), some aesthetic (malocclusion, fluorosis), while some are acute and painful (toothache, pulpitis, oral mucosal lesions, extractions)', according to Hernández et al. (17). Conceptualisation of OHRQoL is context-reliant as culture and society shapes an individual's belief system and influences how health and illness is viewed(18). Studies conducted on children's oral conditions have generally reported a poorer OHRQoL because of the oral conditions (19-22). Herdman et al. purport that OHRQoL measurement domains important to one culture may not be equally relevant in all cultures (10).

Recently, research on children's oral conditions and OHRQoL globally has described the factors influencing OHRQoL (23-26). Oral health-related quality of life research in children is fairly recent in Africa (27-30).Existing children tools that measure OHRQoL have been developed in a non- African setting; however, some have been adapted and tested in the African setting. According to Traebert et al., different existing tools showed discrepancies when applied to different cultural backgrounds when probing the concept of ethnicity and socialisation despite translation (31).With the amount of OHRQoL literature available on children in the African setting, no consolidating integrative review has been conducted regarding the factors influencing OHRQoL. It is, thus, necessary to probe whether the factors influencing OHRQoL are context-reliant.

Consideration of sociocultural contexts and factors affecting children's OHRQoL is important as OHRQoL is a social construct. The majority of health-related quality of life (HRQoL) models are based on the biomedical and psychological dimensions of health such as those in the International Classification of Impairments, Disabilities and Handicaps model by the World Health Organization (ICIDH, 1980). The Locker model is a type of such HRQoL model that is based on the WHO-ICIDH (32). The Locker model is the dental adaptation of the WHO-ICIDH, and the model hypothesises that oral disease will result in 'pain', 'impairment' and functional limitation. These constructs will, in turn, lead to physical and psychological disability, handicap, and thus affect the overall OHRQoL (32). The Locker model places its emphasis on multidimensionality of health positioned around the biomedical model and incorporates a psychosocial dimension.

In 2005, Ferrans et al. developed an OHRQoL conceptual framework which posits that the biological–symptom– functional status complex is directly influenced by both individual and environmental characteristics and together they influence the general perceptions of health and overall OHRQoL (Figure 4.1).(33). Sischo and Broder even unpack the Ferrans et al.'s model further when applying it to oral health by expanding on the individual and environmental characteristics.(26, 33).



Fig 4.1: A conceptual framework of health related quality of life and its determinants

Sources: Ferrans et al.(33); Sischo and Broder.(26)

Oral health-related quality of life in children is particularly important as childhood development involves phases that are dominated by life changes notwithstanding the added burden of living with oral diseases (8, 18, 34). Wallander et al. noted that HRQoL has a dual subjective-objective elements underlined by a time in one's life (4).

Children generally tend to have higher prevalence of oral conditions (35). A review of the life stages before adulthood has not been thoroughly investigated in the broad field of OHRQoL in general and in the African context in particular.

This review is the first to our knowledge that seeks to explore and integrate available literature on the factors influencing OHRQoL in children in the African setting. The review will provide more insight into understanding the phenomenon and to add a voice to the integrated management of children's oral conditions and the related impact on HRQoL.

4.2 METHODS

This review addresses the following question: What are the determinant factors that influence OHRQoL among children in Africa? It seeks to establish, through the available literature, factors influencing OHRQoL in children in Africa. The objective is to integrate and summarise the factors influencing OHRQoL in children diagnosed with oral conditions or problems throughout Africa.

The systematic review was registered with PROSPERO number: CRD42017056759. The inclusion requirements, as shown in Table 4.1, were followed. No publication date limit was set as this type of review has not been done before.

	Included		Excluded			
Publication	Peer reviewed full	text Englis	n Non-English articles			
type	language articles dated	till 2017	Editorials, review articles, letters,			
			practice guidelines, other guideline			
			documents, conference abstracts,			
			conference reports, news articles.			
Study	Any study design with	the				
design	measurement or assessi	ment of				
	OHRQoL using validate	ed tools				
Study	All children studies	and when	e Any study with adult participants			
population	mothers were used as p	roxy of youn	only;			
and study	children.		The study setting was not Africa.			
setting	Studies with overlap up	to adulthoo	1			
	(e.g. 21 years) were incl	luded and th	e			
	outcome referring to a	children onl	У			
	was used in the data ex	traction.				

Table 4.1: Inclusion exclusion criteria of articles in the review

	The study site was anywhere in Africa.				
Condition	Factors influencing OHRQoL	Factors pertaining to dental anxiety,			
of interest		satisfaction and any related topic			
		other than OHRQoL			
Outcome	OHRQoL using validated measures.	Did not use validated measures for			
		OHRQoL			

A systematic literature search of multiple databases with published English language articles in PubMed, CINAHL, EMBASE (Excerpta Medical Database), MEDLINE, EBSCOhost, OVID and PsychINFO was performed with key words: #1 'oral health'; and #2 'quality of life', 'health-related quality of life', 'patient-reported outcomes', 'wellbeing'; and #3 'child*', 'adolescents', 'teen*', 'youth'; and 4# 'determinants', 'factors', 'predictors'; and #5 'oral health quality of life tools/instruments/scales'; and #6 'Africa*'.

4.3 DATA SYNTHESIS

A multi-level search process was used starting with the screening which included an independent review of titles by three of the authors of this article (Y.M.-K., C.B.N., T.R.D.R.). This was followed by a review of abstracts and full articles selected after the abstract review. Thereafter a reference list of selected full articles was reviewed to retrieve more articles. Identified studies that met the publication criteria were grouped into one of the following categories: experimental studies, cohort studies, case control studies and cross sectional observational studies. These studies were then assessed independently for methodological validity by three reviewers, prior to inclusion in the review, using the corresponding checklist developed by the Joanna Briggs Institute tool for cross sectional, random controlled trials and cohort studies. Each of the tools has the components related to selection criteria, validity and reliability of exposure and outcome variables, confounders, objective measurement of outcome and appropriate statistical tests used. Any disagreements that arose between the reviewers were resolved through discussion among the three reviewers. Where required, a consensus of two out of three was the deciding factor. Following assessment of methodological quality, the papers were grouped according to whether they are quantitative, qualitative designs or opinionbased. A data extraction tool was developed specifically for quantitative research data.

None of papers retrieved used qualitative study designs. Three reviewers independently performed data extraction.

Quantitative studies were classified using a table noting publication year, study setting, participants' age, sample size, study design, OHRQoL outcome and the underpinning predictors or factors or determinants, odds ratio (OR) and corresponding confidence intervals (CIs) (Table 4.2).

Aut	hors	Publicatio	Study setting	Facility	Sample age	Sampl e size	Study design	OHRQoL	OHRQoL (Box 1)	tool
		n yeur	seuing			e size	uesign	%	(Box 1)	
1.	Astrom AN, Lie SA, Mbawalla(28)	2016	Tanzani a	School	12-15;16- 21 years	2412	Cohort -Study	50.7%	OIDP	
2.	Birungi N, Fadnes LT, Nankabirwa V, Tumwine JK, Åstrøm AN(36)	2016	Uganda	Community -based	Mothers- [5yrs]chil d pairs	863- 765	#RCT	231% &-26.4%	ECOHIS	
3.	Chukwumah NM, Folayan MO, Oziegbe EO, Umweni AA(37)	2016	Nigeria	Local government area- schools	12-15 years	1790	*C-S study	56.5%	C-OIDP	
4.	Tagelsir A, Eltigani Khogli A, Nurelhuda NM [(38)	2013	Sudan	School	6-18 yrs	79 of 92	*C-S study	15.9%	C-OIDP	
5.	Masumo R, Bardsen A, Mashoto K, Astrom AN(39)	2012	Tanzani a & Uganda	Mother and Child Health clinic	Mothers- [6- 36m]child pairs	1221	*C-S study	32.5- 36.5%	ECOHIS	
6.	Mbawalla HS, Mtaya M , Masalu JR, Brudvik P, Astrom(21)	2011	Tanzani a	School	12-17 years	2678	*C-S study	39.65 %	C-OIDP	
7.	NurelhudaN K, Ahmed MF , Trovik TA, Åstrøm AN(40)	2010	Sudan	School	12yrs	1109	*C-S study	54.6%	C-OIDP	
8.	Mashoto KO, Astom AN, David J, Masalu JR(41)	2009	Tanzani a	School	10-14;15- 19 years	2465	*C-S study	36.2%	OIDP	
9.	Mtaya M, Åstrøm AN, and Georgios Tsakos(22)	2007	Tanzani a	School	13 years	1601	*C-S study	28.6%	C-OIDP	

Table 4.2: List of studies retrieved from the database search

10.	Åstrøm AN,	2003	Uganda		13-15;16-	1146	*C-S	62%	OIDP
	Okulio I.(29)				19 years		study		
11.	\$Mashoto KO, Åstrøm AN, Skeie MS, Masalu JR.[(41)	2010	Tanzani a	School	10-14;15- 19 years	1306	RCT	35.6 %	C-OIDP
12.	\$Hobdell M, Tsakos G, Sprod A, Ladrillo TE, Ross MW, Gordon N, et al.(42)	2009	SA, UK, USA	Schools	15-16;11- 12;40+ years	525	*C-S study	SA49.5 % USA- 52.6% UK28.8 %	OIDP
13.	\$Wandera M, Kayondo J, Engebretsen IMS, Okullo I, Astrom AN. Dentistry. (43)	2009	Uganda	Mother and Child Health clinic	Mothers- [6- 36m]child pairs	816	*C-S study	37.7% Child 47.1% Fam	ECOHIS
14.	\$Robinson PG, Nalweyiso N, Busingye J, Whitworth J. (44)	2005	Uganda,	School	12 years	174	*C-S study	Sum 39.9%	CPQ ₁₁₋₁₄
15.	\$Astrom AN, Mashoto K. (27)	2002	Tanzani a	School	12-20 years	492	*C-S study	-	OIDP Dissatisfactio n [oral condition & dental appearance]

#Randomised Controlled Trial; * Cross sectional Study; \$ excluded from meta-analysis/narrative analysis

UK, United Kingdom; US, United States

 $\ensuremath{^\dagger}$, Excluded from meta-analysis but included in narrative analysis.

C-S, cross sectional study; RCT, randomised controlled trial; OHRQoL, oral health-related quality of life; OIDP, Oral Impacts on Daily Performances; C-OIDP, Child Oral Impacts on Daily Performances; ECOHIS, Early Childhood Oral Health Impact Scale; CPQ₁₁₋₁₄, Child Perceptions Questionnaire.

Box 1 with reference to Table 2: Studies that used validated tools measuring oral health related quality of life

- 1) Family Impact Scale (FIS))(45);
- Child Perceptions Questionnaire (CPQ₆₋₇); (CPQ₈₋₁₀), and (CPQ₁₁₋₁₄)Jokovic et al, (2004)(46-48);
- 3) Child Oral Impacts On Daily Performances (Child-OIDP) Gherunpong et al, (2004)(49)
- 4) Early Childhood Oral Health Impact Scale (ECOHIS) Pahel et al,(2007)(50)

If more than one study reported the same factors influencing OHRQoL, the results were pooled into a statistical meta-analysis.

Where statistical pooling was not possible, the findings were presented in the form of a narrative analysis. The initial step of meta-analysis was to assess the heterogeneity of the studies to be pooled.

When studies were heterogeneous, a random effect model was assumed to account for unequal weighting of the studies. Heterogeneity was quantified using I2 statistic. A variation of 25% or less meant that there was a low heterogeneity of studies, 26% – 50% meant moderate and 56% – 75% implied high heterogeneity. Thereafter a final outcome of interest was read from ORs. Forest plots were created displaying the results from individual studies, together with the summary and 95% CI estimated in the meta-analyses. Random effect models were assumed because of the following reasons: (i) the studies had a wide age range of child participants, (ii) the studies were conducted in different African countries and (iii) studies used different validated tools measuring OHRQoL. Meta-analyses were conducted separately for the same factors. For instance, all studies where dental caries, area of residence, oral problems and socioeconomic status (SES) were factors were analysed separately. Ethical approval was obtained from the Human Research Ethics Committee of the University of the Witwatersrand (Clearance certificate no. M141150).

4.4 RESULTS

A total of 337 articles were retrieved from all databases. Following identification and screening, only 15 articles were assessed for eligibility (Figure 4.2). Of the 15 eligible articles, four were excluded from the narrative or meta-analysis despite using validated OHRQoL tools because they did not perform regression analysis to report on the factors influencing OHRQoL (41-44). The regression analysis was crucial to ascertain the likelihood of independent variables influencing OHRQoL. One article was also excluded because it reported ORs, but the OHRQoL was not the dependant variable in the regression model but the presence or absence of dental fluorosis (27).

The study reported dissatisfaction with oral condition (dental fluorosis) and appearance as the outcome in the logistic regression instead of OHRQoL(27). Finally, only ten articles were included for analysis.



Figure 4.2: PRISMA flowchart depicting the flow of information through different

4.4.1Characteristics of the studies finally included in the review

The main characteristics of the studies in the review are shown in Table 4.2. All of the ten studies used validated tools to measure OHRQoL outcomes (Box 1).

All studies were quantitative in design; nine were conducted in the East African region (Tanzania, Uganda and Sudan); they were also similar in sharing the same authors or co-authors (21, 22, 28, 29, 36, 38-41, 51). Only one study was conducted in West Africa (Nigeria)(37). The study designs were biased towards cross sectional studies with eight out of 10 (80%) using that design. The measure of association of interest was OR and the related CIs.

4.4.2 Factors influencing oral health-related quality of life where studies were fitted into forest plots for meta-analysis

4.4.2.1Dental Caries

Six studies in this review reported the presence of dental caries as a factor influencing OHRQoL (21, 28, 37, 39, 40, 52). Four of the studies were performed in Tanzania with a total of 7617 children and they reported the variable dental caries experience measured by DMFT/dmft (Decayed-Missing-Filled Teeth/decayed-missing-filled teeth) index. In both primary and secondary dentition, the caries index ranged from being 1.5 times more likely to up to 5.2 times more likely to lead to a poorer OHRQoL among children. Studies based in the Sudan and Uganda reported mid-range ORs of 2.0 (95% CI: 1.4-2.6) and 1.8 (95% CI: 1.2-3.0), respectively (n combined = 1874) (Figure 4.3).



Fig 4.3: Forest plot for dental caries and OHRQoL

Dental caries, when fitted for meta-analysis, showed an overall high level of influence with regard to OHRQoL in total combined studies of 9491 child participants. However, the results of the I2 statistics showed that the studies were heterogeneous (88%, p = 0.000) (Figure 4.3). This implies that the studies cannot be pooled because of high heterogeneity. Even though studies all used validated OHRQoL (Table 4.2), responses are still subjective heterogeneity and the overall conclusion from meta-analysis is explained later in the discussion.

4.4.2.20ral Conditions Other than Dental Caries

Mashoto et al. in their Tanzanian study reported, with a total of 1745 children with a mean age of 13.8 years (s.d. 1.67), that having any oral condition other than dental caries increased the odds of a poorer OHRQoL (OR: 3.8, 95% CI: 2.8–5.2)(52). The results were the same as those of Mtaya et al. in Tanzania (n = 387) (OR: 3.9, 95% CI: 2.9–5.2)(22). These authors, using the Child-OIDP validated tools (Table 4.2), suggested that the oral problems were stronger influencers than other dimensions in the OHRQoL tool used, such as emotional and social wellbeing (22, 52). When these studies were included in the meta-analysis, having oral problems (excluding dental caries) was still a factor likely to influence OHRQoL among children (Figure 4.4). Both the I2 test for heterogeneity favoured homogeneity of the studies (0.0%, p = 0.9) (Figure 4.4).



CI, confidence interval; ID, identity; ES, effect size.

Fig 4.4: Forest plot for oral problems other than dental caries

4.4.2.3 Socio-economic Status

From the only longitudinal study in the review, with a sample of 2412 children in Tanzania, the authors concluded that an SES was 2.3 times more likely (95% CI: 1.12-4.78) to result in poorer OHRQoL (Figure 4.4), both used C-OIDP and OIDP tools (Table 4.2)(28). Åstrøm et al. concluded that having parents who could afford dental care was a significant predictor of positive OHRQoL (28). Equally, in 2010 Nurelhuda et al. in their Sudanese study (n = 1109)

found that SES, albeit in a cross sectional study, was 1.9 times more likely (95% CI: 1.1–1.3) to influence OHRQoL. (40)

Meta-analysis of the two studies was displayed in the forest plot and supported the fact that a higher SES is 2.03 times more likely to influence OHRQoL outcomes (Figure 4.5).



CI, confidence interval; ID, identity; ES, effect size.

Fig 4.5: Forest plot for socioeconomic status

4.2.2.4 Area of Residence

The Tanzanian and Ugandan studies found the area of residence (district, rural and urban) to influence children's OHRQoL (22, 29). Nurelhuda et al. reached a similar conclusion in the Sudanese study (40). The meta-analysis of these studies, with a combined sample of 3202 participants, supported the notion that the area or residence is a significant predictor of OHRQoL (Figure 4.6).



Area of residence as a factor influencing OHRQoL Outcome

CI, confidence interval; ID, identity; ES, effect size.

Fig 4.6: Forest plot for 'area of residence' status influencing OHRQoL 4.4.2.5 Satisfaction with Oral Health

In the Sudanese and Tanzanian studies those children who were satisfied with their oral health status were less likely to report lower OHRQoL using the Child-OIDP tool (OR: 0.4, 95% CI: 0.3-0.6)(22, 40). However, the studies demonstrated moderate heterogeneity and the metaanalysis yielded contrasting findings. The overall effect was not significant with OR = 0.87(95% CI: 0.19–4.00) with equal weighting of the studies (Figures 4.7–4.9).



CI confidence interval; ID, identity; ES, effect size.

Fig 4.7: Forest plot for 'satisfaction with Oral health' and OHRQoL

4.4.2.6 Dental Attendance and Gingival Infection

Both dental attendance and gingival infection were identified by Mtaya et al., Mashoto et al. and Nurelhuda et al. as factors influencing OHRQoL in their Tanzanian and Sudanese samples, respectively(22, 40, 52). The meta-analysis and pooling of results did not support their argument. Dental attendance had an overall effect of 1.30 (0.48–3.50), while gingival infection had an overall effect of 1.40 (0.88–2.24) (Figures 4.7–4.9).



CI confidence interval; ID, identity; ES, effect size.





CI confidence interval; ID, identity; ES, effect size.

Fig 4.9: Forest plot for 'Gingival Infection' and OHRQoL

4.4.3 Seven more reported factors influencing oral health-related quality of life

Four studies, in addition to reporting factors similar to each other, also reported individual factors that were not cited by any other authors in this review. In the Sudan, among the visually challenged school attendants, it was found that visual impairment (n = 79, OR: 6.3, 95% CI: 1.7–22.7 [Results are significant]) significantly influenced OHRQoL (38).

Low self-efficacy (n = 610, OR: 0.41, 95% CI: 0.19–0.89 [Results are significant; paper was included in meta-analyses]) and *depressed mental status* n = 428. OR: 3.23 (95% CI: 1.37–7.63 [Results are significant]) (paper was included in meta-analyses) were reported to be significant predictors of OHRQoL in the secondary schools learners in Tanzania.(28) A Ugandan study by Åstrøm and Okullo cited that *religious affiliation* (n = 256, OR: 0.5, 95% CI: 0.3–0.9 [Results are significant; paper was included in meta-analyses]) and *missing teeth* (n =372, OR: 1.8, 95% CI: 1.0–3.2 [Results are significant; paper was included in meta-analyses]) significantly influenced the OHRQoL of adolescents using the OIDP tool, and were significantly influenced by OHRQoL instead (28, 29, 40).

Of interest is that a study conducted among the Sudanese sample of 12-year-old school attendees showed a significant association between OHRQoL and behavioural factors, such as irregular tooth brushing and eating sugar sweetened snacks (16, 28). The findings included *tooth brushing frequency (irregular)* (OR: 1.0, 95% CI: 0.6–1.7), *plaque index* (n = 1045, OR: 1.3, 95% CI: 0.9–1.8) and *sugar sweetened snack intake* (n = 1045, OR: 1.4, 95% CI: 0.9–1.8), respectively.

4.5 DISCUSSION

This systematic review is the first aimed to critically analyse the factors influencing OHRQoL in African child populations. Oral health-related quality of life outcomes are usually assessed by measurement tools based on a conceptual framework which postulates that individual factors (demographic, personal biological and psychological status) and environmental factors (SES, dental access, caregivers status, education, type of residence and utilisation, and more) influence general health perceptions and the overall OHRQoL as postulated by Ferrens et al.(33).

All ten articles included studies that used validated tools to measure OHRQoL in children (Table 4.2). The studies used good methods with regard to selection criteria of participants,

validity and reliability of exposure and outcome variables as objectively assessed by the review involved (Y.M.-K., C.B.N., and T.R.D.R.). There was also a predisposition towards cross sectional study designs in the studies selected. Cross sectional studies cannot determine causality but only associations. However, these associations were rigorously determined especially when studies adjusted for confounders using regression analysis. Longitudinal studies including randomised controlled trials are obviously preferred as these designs have the potential to follow up on the exposure variable and can be used to determine causality.

The bias of studies towards East Africa could be attributed to one key author who contributed to eight of the ten articles. The reason could be that the field on OHRQoL in dentistry is still at its development stage in Africa and the author is an expert author in the field.

Dental caries, the most common dental condition that affects 60% - 90% of school-aged children, in children more often results in pain and functional limitation (52). Thus, pain from severe dental decay can exert an impact on OHRQoL (53). The analysis in this review revealed an unexpected result regarding dental caries where it was not conclusively a factor that influenced OHRQoL. The result may be described by several explanations.

Firstly, there was a high level of variation in the studies that reported on dental caries as a factor influencing OHRQoL. Heterogeneity in the studies within a systematic review is expected because a review combines studies that may be methodologically diverse; hence, it is more important to determine the extent to which heterogeneity affects the conclusions to the studies (54). A high percentage of I2 statistic (> 75%) indicates that there is an increased level of variability among the studies that could be because of the differences in their OHRQoL tools, studies adjusting for different confounders as well as the high number of studies included in meta-analysis which increases the percentage of the I2 statistic (55). Although all tools used were validated in the study settings, two tools (Child-OIDP and OIDP) (21, 28, 37, 39, 40, 52). , were used where dental caries was reported to be a factor. Secondly, the heterogeneity could be attributed to the subjective nature of the design of OHRQoL tools that may be affected by cultural variation and differences in these East African countries. Thirdly, reporting of caries experience through DMFT/dmft without severity does not factor the element of pain. Indices such as Pulpal involvement, Ulcerations, Fistula and Abscess (PUFA) index do factor in the pain element, and thus may be useful in OHRQoL measurements (56). Fourthly, the DMFT/dmft index measures caries experience and is diluted by the filled and missing components related to treatment. It would be preferable for the analysis to single out the

DMFT/dmft component to assess the active decay status when association analysis is performed. Lastly, the East African region is characterised by high fluoride content in the water source which makes teeth mottled and prone enough to initiation of dental caries, but the lesions are not severe because of the protective nature of fluorosis teeth(57).

Dental caries was reported as a predictor of pain only if the prevalence and severity is high which tends to be common in the poorer communities who consume more refined carbohydrates diet as is common in South Africa (35).

A Norwegian study by Koposovo et al. also supports the notion that the impact of dental caries on OHRQoL can be weak, and they attribute this finding to low general prevalence of caries in their Norwegian adolescent population (58).

Oral conditions other than dental caries were a significant determinant of OHRQoL in this systematic review. These oral conditions maybe gingival or mucosal conditions, related to aesthetics or dental treatments. This is plausible as OHRQoL dimensions include pain, functional, psychological or emotional factors as well the social impacts. Malocclusion, which is an oral problem where there is misalignment or an incorrect relationship between the two dental arches, may result in aesthetic and functional problems. This is more likely to lead to a self-perceived treatment need which is common in malocclusion cases. It heightens the way the children perceive their own oral health. The children tend to have a worsened OHRQoL when they perceive that they ought to receive treatment, a perception that is shaped by the societal expectations. Appearance, which is affected in malocclusion cases, is very important in children's lives particularly as they approach puberty. The notion is supported by Koposova et al.'s study in Europe among 12-year-olds where it was concluded that dental aesthetics was found to influence their OHRQoL (58).

Socioeconomic status measured by attending private versus public school was found to play an important role in influencing OHRQoL in the review. A higher SES may result in preventive visits and better access to dental health services and, thus, is likely to result in improved dental health, no pain, no early extraction and resulting malocclusion and a better OHRQoL. Thus, a better SES increases access to aesthetic services and may possibly influence the non-clinical dimensions (behavioural and social) of OHRQoL. Issues such as missing teeth, early extraction and later malocclusion are averted early, and thus improve oral health perceptions of adolescents.

This finding in this review is congruent with literature where parents' low income is closely related to the availability of resources and children from low income families are likely to have a lower OHRQoL (59, 60). In addition, the study among 12-year-olds in Norway and Russia reported a poorer OHRQoL for the less privileged Russian children than their Norwegian counterpart(61). Furthermore, a study of 12-year-old Thai children of low socioeconomic status found that they were likely to have a high level of dental caries with subsequent negative OHRQoL impact (61). So, this review in the African setting characterised by low income countries with few resources also confirmed that resources will invariably influence OHRQoL. These findings highlight the context-related dimensions of most OHRQoL frameworks. Unfavourable social conditions and poor SES have a negative impact on children's OHRQoL. (62) Locker states that in the Canadian study, low SES scored worse than high SES (63).

There was evidence linking *area of residence* with negative outcomes on OHRQoL in African child populations from this review. Mtaya et al. and Åstrøm and Okullo, (22, 29) in their Tanzanian and Ugandan studies, found the area of residence (rural vs. urban) to influence children's OHRQoL (8, 16). Nurelhuda et al. reached a similar conclusion in their Sudanese study ((40). Rural districts tend to have poor availability and less access to dental facilities. Reduced access is likely to result in less preventive and curative services which might affect OHRQoL outcomes on various levels such as pain, functional and psychological impact. Children in urban dwellings tended to have or report better OHRQoL outcomes because of socio-demographic characteristics such as better parental education (22). One can argue that SES will be a mediating factor to the area (urban or rural) where children reside. If both factors have a strong relationship with the dependant variable, then there is a chain of risk factors that an even worse off outcome regarding OHRQoL may prevail (64).

Satisfaction with oral health is likely to result in a good self-rating on oral health and it is influenced by attitudes towards oral health.

The result from this review showed moderate heterogeneity, and meta-analysis showed that this factor did not influence OHRQoL from the only two studies in the review.

Satisfaction with oral health usually results from the individual's attitudes; these attitudes are shaped by socialisation and context. In contrast, studies conducted outside Africa from literature have shown that oral health perceptions and attitudes of the caregiver or parents and of children themselves can influence the OHRQoL in children (53, 65). Shaghaghian et al.

reported that parental attitude to children's oral hygiene habits influences children's oral health status and their OHRQoL (65). Gomes et al. conclude that those caregivers who viewed their children's oral health as poor were more likely to report a greater impact on OHRQoL (54). Different children in different geographical areas such as Saudi Arabia, Brazil and the United Kingdom responded differently especially on the social wellbeing and emotional wellbeing constructs of OHRQoL instruments, despite the translation and adaptation of the tool (46, 66-68). The difference can be explained by embedded cultural influences. It is for this reason that the development of a conceptual equivalence of OHRQoL measurement tools is recommended before it can be used in settings different from those in which it originated (10).

More Factors Influencing Oral Health-related Quality of Life

Physical handicap such as visual impairment will impart an element of physical limitation, thus it may result in restrictive action and lack of visual–manual coordination. Despite the low sample in the reviewed study, of note among these visually impaired school attendees, those who were boarders had a poorer oral hygiene compared with non-boarders. Therefore, lack of assistance and supervision by caregivers may have mediated the resulting poorer oral hygiene. Less or no assistance with oral hygiene practices (e.g. tooth brushing and use of mouth guards) may thus lead to poor oral health states such as poor oral hygiene and traumatic dental injuries. A poor oral health status and the associated oral conditions may cause a negative reporting on OHRQoL (38). Irregular tooth brushing among the 12-year-old non-visually disabled Sudanese children in a similar setting did, however, not lead to a poor OHRQoL, perhaps the traumatic injures carried more weight in the OHRQoL reporting rather limited manual–visual brushing coordination (40).

Mental status is closely related to perception of self; if individuals have less confidence and suffer from depression then their attitudes are generally negative. (69). The reporting of OHRQoL is subjective in nature, thus the psychological dimension of the OIDP tool used among the Tanzanian school learners carried more weight than the clinical factors because of their depressive symptoms (28). The authors caution against a conclusion based on the mediating factor related to dental care utilisation, which was generally poor in the Tanzanian setting. However, a prerequisite for good oral health behaviour is self-efficacy to, for example, use floss, regular brushing and proper diet, according to the theory of planned behaviour (70). Self-efficacy may be lacking in the depressive states situations.

Behavioural factors such as poor dietary habits and irregular brushing on their own failed to make an impact on these African child populations; however, they may be mediated by the level of adolescents' self-efficacy. (28) or by assistance or support in self-care. (38). Socioeconomic status is an important mediator or moderator in this instance because it will increase the dental attendance patterns and enhance preventive behaviour.

Religion such as reporting being Muslim was an important factor in the Ugandan adolescent sample as they were less likely to report oral impacts (29). Religion and spirituality are rarely reported in the health-related patient-reported outcomes. O'Connell and Skevington pointed out in their review that when the idea of spiritually is visited, it is usually as part of the social or psychological phenomenon of HRQoL outcomes and not a stand-alone dimension. Not enough is reported about religion, and it tends to be a salient concept in the OHRQoL(71).

The issue of a child's age as a determinant factor did not come up in the African studies in this systematic review, although Barbosa and Gaviao argue that the child's age, development and gender influence and affect their wellbeing (72). Studies included in the review did adjust for age and gender, and in both instances there were no significant predictors. Except for two studies that used caregiver reports, most used adolescents groups of comparable ages (Table 4.2). Genderson et al. argues that the issue of self-concept is age-dependent and is heightened and important during adolescence because oral health is 'strongly age-dependent',(60) hence there are differences between children and adults in OHRQoL measures (73).

Dental utilisation and access did not influence OHRQoL in this review when results were pooled; this is in contrast to the Indian study by Kumar et al. which found that OHRQoL was better for participants who had been to the dentist within the past 12 months (74). Dental utilisation increases when dental access is enhanced. However, unlike in Kumar et al.' Indian study (74), it was surprising in the Ugandan study that there was an inverse relationship where higher utilisation led to poorer OHRQoL reports (29). Nonetheless, following pooling the results in the meta-analysis, dental utilisation was not an influencing factor in this review. Introduction of free primary services in other African settings has shown the increased work operator load experience and thus poor services (75).

In Uganda, the Lira District has a free user-fee policy for a public oral service in place. Userfree policies may lead to poor services, thus affecting OHRQoL directly as the perceptions are rated by experience during dental visits. A key finding in the articles reviewed was that factors influencing OHRQoL in children were environmental in nature (family SES and area of residence), but depended on the individual biological status and symptoms from oral problems. These oral problems, however, did not include dental caries, the most common oral condition.

When assessing the findings against the Ferrans et al. (33) and Sischo and Broder's (26) conceptual frameworks on OHRQoL, individual characteristics pertained only to the biological status and not the demographic factors. Sischo and Broder's framework goes further to unpack the individual characteristics (Figure 4.1). There seems to be congruence with the Sischo and Broder explanation of the framework in this African setting where oral medical condition, psyche status (low self-efficacy and depressive states) and physical disability of the children were the significant individual factors to influence. However, the environmental issues arising from the review were the area of residence and SES only. The parent or caregiver status was implied by the family's SES status.

The factors in the review were balanced between the environmental and individuals' oral problems, but the pathway did not necessarily fit the models (Figure 4.1). Overall perceptions with oral health were not evident. Other factors such as oral health behaviour, perception or satisfaction with oral health and dental access were significant in other settings in high income countries but not evident in the African setting. This may be related to contextual importance of factors or perhaps these factors were reported by few studies (76). It is evident from the review that the OHRQoL measurement tools do not tease out in the setting what is reported in high income country settings. The form and degree of impacts could vary between populations with different cultural backgrounds (77). The question is: How are issues framed and from whose point of view that they fail to capture or be relevant in the setting?

Moreover, these systematic review findings are in contrast with the Locker model of OHRQoL, which suggests that mainly physical symptoms and functional limitation dimensions will carry weight rather than environmental dimensions in influencing OHRQoL(19) .The biomedical Locker model hypothesised that oral disease will result in 'pain', 'impairment' and functional limitation.

These constructs will, in turn, lead to physical and psychological disability, handicap, and thus affect the overall OHRQoL (32). Thus, in this African setting context the contributing factors spanned the socio-environmental context in nature and biomedical dimensions.

Oral health-related quality of life does not exist in a vacuum, but is influenced by interplay of socio-economical, biological and personal psychosocial factors. Herdman et al. argue convincingly that cross-cultural adaptation is warranted as it guards against automatic assumptions that OHRQoL domains important to one culture will be equally relevant in all cultures (10). Comprehension of this interplay will begin a process to assess the OHRQoL impacts, hence the importance of studying the factors of OHRQoL. Understanding influencing factors will assist in planning so that measures to reduce OHRQoL impacts are incorporated in the integrated management of children's oral health in Africa.

4.6 LIMITATIONS

Mostly cross sectional studies were retrieved from this review given that research into OHRQoL is fairly recent in Africa. However, data analysis included accounting for possible confounders when looking for associated factors related to OHRQoL in children. The reporting of ORs implied that authors dichotomised the OHRQoL outcome describing the absence or presence of a negative impact. Reporting the presence of OHRQoL impacts in binary form makes it impossible to see the intensity of the OHRQoL impacts.

4.7 CONCLUSION

There is preliminary evidence to suggest that in Africa there is an association between individual factors such as children's psyche and oral problems, excluding dental caries, and contextual social determinants such as area of residence and SES and children's OHRQoL in African contexts.

Thus, in this African setting context the contributing factors spanned the socio-environmental context in nature and biomedical dimensions. There seemed to be a contextual viewpoint underpinning the current OHRQoL frameworks and OHRQoL was context-reliant.

There is evidence of rigorous work in the field of OHRQoL in Africa. However, most literature is dominated by quantitative prevalence studies. More work in qualitative and longitudinal studies can assess causality in this field in the setting to see if factors related to OHRQoL are context-reliant.. On the contrary, a newer model, such as the International Classification of Functioning, Disability and Health (ICF), has an elaborate classification which includes holistic non-sick-based dimensions such as functioning and health. These models and theories provide a guiding point of view when interrogating the factors that may influence OHRQoL among African children.

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CHAPTER 5 : Understanding the perceptions and experiences of oral conditions and oral health-related-quality of life among HIV infected and undiagnosed adolescents in Johannesburg, South Africa

Title of	Understanding the perceptions and experiences of oral conditions
publication	and oral health-related-quality of life among HIV infected and
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The second objective of the study project was the development of a new tool or cross-culturally adapting a tool to new setting it was not developed from. Literature advises that before any tool is developed some of the steps include finding out from the population the tool will be used on, the perceptions, expressed and with felt feelings on their experiences about a phenomenon. A qualitative exploration of the concept of the oral health and the how it affects the individual when oral disease is reported in a new context is important to guide the next steps of tool adaptation. All the above was done guided by the conceptual framework in the field of health related quality of life and the oral-health-related if life which postulates that the two anchors; the circumstance of the individuals and the environment they live in, influence their overall general perception to influence their on oral-health-related quality of life. This chapter is a published paper with the citation mentioned. It seeks to understand the perceptions and experiences of oral conditions and oral health-related-quality of life among HIV infected and undiagnosed adolescents in Johannesburg setting. The findings would guide the necessity of a new tool or adapting tool and incorporate the themes arising from there to make it context relevant.

Abstract:

Introduction: High occurrences of oral diseases among HIV infected children and adolescents raise concerns about their Oral Health-Related Quality of Life (OHRQoL). The applicability of existing assessment tools for OHRQoL has not been investigated in South Africa.

Methods: This study assessed an existing tool by exploring the perceptions and experiences of OHRQoL among adolescents living with HIV (ALHIV) in Johannesburg. Twenty-five indepth-interviews of both ALHIV and HIV undiagnosed adolescents were conducted and thematically analysed to identify arising themes.

Results: Three broad domains and eight themes were identified: (1) individual-level: oral health awareness, felt oral symptoms, impaired oral functioning and coping; (2) external factors: access to and negative experiences of using health services; and (3) social level: social interaction and self-stigmatisation.

The adolescents' understanding of oral health concurred with global definitions. ALHIV reported HIV-related self-stigmatisation perpetuated by more oral symptoms and oral impairments (speaking, eating and teeth-cleaning) and more self-care and coping practices.

Conclusions: The perceptions and experiences of OHRQoL among ALHIV in Johannesburg were influenced, as elsewhere, by a combination of self-perception and social inter-actions, together with the state of their structural environment and biological wellbeing.

High values were placed on coping, symptom endurance, resilience and dental health service experiences. These findings may be relevant in meeting adolescents' oral health needs and improving services.

Key Wordship, oral health, qualitative interviews, quality of life, South Africa, adolescents.

5.1 INTRODUCTION

According to global reports, there are nearly 2.1 million adolescents (10-19 years) living with HIV Infections (ALHIV)(78). About 84% live in Sub-Saharan Africa. Of the 7.1 million South Africans living with HIV in 2016, approximately 370,000 (240,000 - 520,000) were adolescents aged 10-19 years (79).

ALHIV remain vulnerable to oral diseases (13) and have high unmet oral health care needs despite their regular use of antiretroviral treatment (ART) services (80, 81). Studies conducted on children outside South Africa (SA) have reported a poorer oral health-related quality of life (OHRQoL) due to oral diseases in ALHIV when compared with HIV uninfected children (19, 20, 30). This may or may not be the case for South Africa given that OHRQoL varies with sociocultural and economic factors (72, 82).

Oral health influences people physically and psycho-logically; it influences how they grow, look, speak, chew, and socialise, as well as their feelings of social wellbeing. Thus, oral health is essential and fundamental to the quality of life as it ensures social and physical wellbeing (83).

Glick and co-authors in 2012 defined oral health as including: the ability to speak, smile, smell, taste, touch, chew, swallow, and convey a range of emotions through facial expressions, with confidence and without pain, discomfort, and disease of the craniofacial complex" (15).

The conceptualisation of OHRQoL is context-reliant as it highlights social relationships in a social environment. Koot added that health-related quality of life has dual subjective-objective elements underpinned by the phase in one's life (84).

Adolescent patients have distinctive oral health needs, characterised by mixed to permanent dentition, a period of notable caries activity and a higher prevalence of gingivitis. They have heightened vulnerability to environmental factors such as diet, independence to seek care, compliance to care, low priority for oral hygiene (85), self-image and social acceptance (73, 86). This phase of life has a myriad of life changes besides the added considerations of living with the HIV infection.

The high burden of oral diseases among HIV infected children and adolescents in South Africa is well documented (87, 88). However, there are gaps with regard to information on the impact of the oral conditions on the OHRQoL of HIV infected adolescents.

A review of the literature indicates that none of the existing quantitative tools that measure the quality of life in oral health have been developed in the African setting. Thus assessing their local applicability is essential as non-adapted tools may be culturally invalid. Existing OHRQoL tools showed measurement bias when interrogating attributes such as ethnicity due to their inherent theoretical biases (31).

Sischo and Broder proposed in their 'Theoretical Model of OHRQoL' that the biologicalsymptom-functional status complex of oral conditions is directly driven by both individual and environmental characteristics and these overall exert an influence on OHRQoL (26).

However, various scholars in the field argue that the frameworks and models consistently underscore the importance of the sociocultural context and its complex interplay with other critical determinants of OHRQoL (89, 90).

Against this background, this paper seeks to understand the perceptions and experience of OHRQoL among ALHIV in Johannesburg, South Africa and, further, to explore the applicability of the tool that has been developed for the theoretical framework; namely, the Child Oral Health Impact Profile (COHIP) measure (26).

5.2 METHODS

The relationship of ALHIV oral health status with the OHRQoL was explored in a qualitative study design using the theoretical model of oral health-related quality of life framework. The study respondents comprised both HIV positive adolescents aged 14-19 years receiving treatment at a Johannesburg ART Wellness Centre and HIV undiagnosed adolescents recruited from public schools located in the Johannesburg central business district, having similar participant profiles and demographics. Johannesburg is a cosmopolitan, multicultural urban city with a high African migrant population, estimated to have a population of nine million people. The city presents a diverse cultural and ethnic background with a potential to influence the OHRQoL.

In-depth interviews (IDIs) were used to collect information to fulfil the study's objective. IDIs can provide an undiluted focus on the individual as the adolescents may not feel free to talk about their infirmities and matters bordering on their personal issues in a focus group discussion (90). Each adolescent and parent/guardian received an information sheet about seeking parent/guardian informed consent for both the interview and audio recording of the process, while the adolescents provided assent.

The Human Research Ethics Committee of the University of the Witwatersrand (M161142) approved the full study protocol. Interviews were carried out until thematic saturation was reached.

The participants were asked about their perception of OHRQoL and their experiences of how oral conditions affect their daily activities. The adolescents were probed further for any response given to elicit frequency and severity of problems (if any). Two trained researchers conducted the interviews. Semi-structured interviews were conducted following the interview guide to ensure consistency and trustworthiness. In addition to guiding an open exploration of personal accounts on experiences and views about oral health conditions, the interview guide assisted in exploring the value placed on oral health and assessed the severity of impairment resulting from the oral health conditions.

The IDIs were conducted in a room at the study sites. The interviewers were cognizant of reflexivity, i.e., the ability to evaluate one's own biases and preconceptions. This was done by bracketing; the process of setting aside one's personal experiences, biases and prior notions (91). Bracketing involved engaging in dialogue with fellow researchers during the conceptualisation stage of the research proposal, and noting down all personal viewpoints.

Then, during the interview stage, daily discussions were held to recognise and to isolate personal bias or preconceived notions. At the conclusion of the interview there was an opportunity for adolescents to ask questions and report any relevant information.

Data management and analysis occurred concurrently. IDIs from both wellness and school sites were transcribed verbatim by the research team and analysed using thematic content analysis. Firstly, the research team read transcripts independently without any coding. The second reading of the transcripts occurred, and initial 'codes' were assigned to a group of text.

A mind map visualising the data was run using NVivo software to identify frequently used words which was helpful in understanding the feedback. To enhance the trustworthiness of the process, three independent coders analysed the transcripts. The initial categorisation of themes led to the definitions of the 'arising' codes.

The three coders came up with a list of different codes and in discussion reached consensus on the final initial codes based on the study objectives. The third stage involved discussions with different researchers, investigating the relationships between initial codes to enable reduction of the codes to higher order final themes. Eight themes were identified, and these were later regrouped into three higher order domains, all congruent with the propositions in the reference conceptual framework on OHRQoL (26, 89).

Twenty-five adolescents, 14 females and 11 males ranging from 14 to 19 year olds (Table 5.1) participated in the IDIs until no new information was retrieved.

Table 5.1: Distribution of participants in the study

	Male n=11	Female n=14	Total =25
School site (14-16yrs.)	5	7	12
Wellness site (15-19	6	7	13
yrs.)			

5.3 BROAD QUALITATIVE FINDINGS

Following the objective to explore the understanding, perceptions and experiences of the adolescents in Johannesburg regarding their oral health and oral health-related quality of life, eight themes were identified that fell into three broad domains: individual factors, external factors and social impact factors (Figure 5.1).



Figure 5.1: Themes and categories identified from the transcripts

5.3.1. Individual-level Domain

5.3.1.1 Oral Health Awareness

Adolescents were asked to share their understanding of oral health as a 'concept'. They reported that 'dental health' refers to the presence of dental signs and symptoms of the oral disease; poor habits or good dental health. Knowledge of oral health seemed optimal. When asked "What can you tell me about dental health?" one participant summarised:

"Dental health refers to your teeth, your mouth and taking care of them and all that." - (Male 16 years, Wellness site)

Those participants from the school site described oral health as related to the behavioural practices such as taking care of teeth. ALHIV group related oral health to the effects of bad behavioural practices and to the presence or absence of symptoms. The remark 'taking care of' implied the participants put the responsibility and ability to self.

"Dental health means that if you don't brush your teeth, your mouth always smells when you talk to people." - (Male 18 Years, Wellness site)

"Dental health means I'm not taking care of my teeth & my teeth are rotten & stuff like that." - (Male 15 years, School) ALHIV described 'dental health' based on their perceived health seeking behaviour; once more, mention of absence or the presence of problems in the mouth or teeth.

"Dental health refers to anything concerning teeth; taking care of them and keeping them fresh. Dental health is treating your teeth like going to the dentist and checking what is going on. Also, is when you do not have teeth problem or paining or has holes." - (Female 15 years, Wellness)

Both groups of adolescents displayed an understanding of oral health.

5.3.1.2. Oral signs and felt symptoms

The 'oral signs and symptoms' emerged most often in the interviews. ALHIV generally reported more felt symptoms and signs of oral disease than did their counterparts. Among the symptoms most frequently mentioned were pain, bleeding gums, bad breath, dry lips and mouth, sores on the mouth, sores on the tongue, and decayed teeth. When asked about the frequency and intensity of the symptoms, they reported variable levels of intensity, rated from one to ten, with ten being the most intense on a visual analogue scale. There were reports of sores on the tongue that were rated eight out of ten. One participant from the school site reported being affected by bad breath and bleeding gums, rating his feelings at nine. Generally, female adolescents expressed symptoms.

"I have rotten teeth but not bleeding gums. It pains nearly twice a week. Especially when eating when I have tonsils and sores. Swallowing and chewing, sucking is painful.

Taste is also affected because I taste something different. That makes me to stop eating." (Female 16 years, Well-ness site)

5.3.1.3 Oral Functioning

The ways in which symptoms impacted on oral health functions were coded separately. These functions included speaking, eating, cleaning/brushing teeth, and swallowing. Functioning was generally equally reported across the two research sites and across both sexes. When asked about the role of teeth and the mouth in daily activities such as eating, schoolwork, speaking: one respondent replied:

"I am affected, especially eating, when I have tonsils and sores. Homework and sleeping are not affected. Swallowing and chewing, sucking is painful. Taste is also affected because I taste something different. That makes me to stop eating. This affects twice a month.... I love eating, but it makes lose appetite. I get disturbed with brushing because I end up doing it once"

5.3.1.4. Coping and Self-care

A theme emerged of coping and self-care in oral conditions management. The coping mechanism was defined as managing the symptoms and included self-help home remedies treatment of orofacial condition signs and symptoms without seeing a health professional.

Despite adolescents reporting a high frequency and strong intensity of oral symptoms, they mostly had ways of managing or coping with their oral problems. There was an element of being strong and resilient to the oral symptoms experienced. There was a will to take action to solve matters or 'live with the condition' attitude. For instance, when asked 'how do you feel about teeth and mouth problems'; two adolescents shared the following:

"It's very bad sometimes I feel like I can spit out whatever that I'm eating... but I never actually spit it out, I just find a way to withhold the pain, and I act like I'm fine." (Female, 16 Wellness site).

"Sometimes I feel very uncomfortable especially when I talk because of the smell. My mom told me I have a smelly mouth. I wasn't aware of it. She bought the spray for me, and I get ok. Pain makes me not to chew on that side. This makes me feelnot sure.....but now I am used to chewing on one side." (Female 15 years, School)

5.3.2 External Factor Domain

5.3.2.1 Dental Access

Another emergent theme was related to the use of the dental services and the issues around using dental services. Dental access referred to the adolescent acquiring dental services for the problems experienced. Access would at times be related to the distance to the dental facility, which was a problem for some.

"The clinic is far though. I struggle with transport, but I go, sometimes I walk to the clinic. I get money from my mom; I do get support from people I stay with." (Female 16 years, Wellness site.)

In addition to distance, adolescents spoke about cost as a hindrance to using dental services.

"When I brush my teeth, I always have stains. It is better ever since I started using Sensodyne. But I still have problems. My problem is the filling. When I eat, I have toothache, and I eat on the other side for chewing. I endure pain 'cos I don't have money for the dentist. The private dentist you pay." (Female 16 years, Wellness site)

Another participant reported that remembering past pain would push her to seek dental treatment.

"I needed to take out teeth about six years and was in theatre. At first, I was scared, and my mom told me it has to be done 'cos they are bad. She reminded how it was for me hurting before we came to the clinic. I was scared, but we went to the clinic. When we were at the clinic, it became even be sorer, so there was definitely no turning back." (Female 16 years, Wellness site)

5.3.2.2 Dental Experience

A theme on past experiences arose, referring to both the good and bad experiences related to the dental services which had been acquired. This theme was closely related to access, as previous experiences had the potential to influence the accessing of dental services. One adolescent shared a very negative and traumatic experience, which she linked to her limited choice of service provision. It was encouraging to note that she acknowledged that the bad experience was an isolated event that might not occur again because 'doctors (dentists) are not the same.'

"It was very painful. I think the injection and the extraction contributed to the pain. I told them it was painful and they told me to sit still. They need to ask people to come check their teeth. Getting to know what they do in their daily live. As for my experience, they should have listened to me and left me alone. I mean I told them it was sore, but they continued taking it out. I might go back again 'cos doctors are not the same. Nothing positive happened during my dental visit, the extraction was very bad." (Female 18 years, Wellness site)

The dental experience was influenced by the perception that free public dental services are of poor quality. The adolescents end up not being empowered about their oral health.

"They do not check the tooth but they give me treatment (tablets). I don't feel good cos I end up not knowing what is wrong with me. The free service clinics they don't at-tend well, and 101 they will tell you to take it out. They take out teeth badly. I have been there [public clinic] once, and I had a bad experience when I went to take out my tooth, they didn't take it all out. I had to go back to the dentist [private], and they filled it, and my experience was good." (Female 16 years, Wellness site.)

Not only bad service experiences were described in the interviews; some reported positively about the health personnel's right attitude and warmth.

"I had that bad dental experience when I was sick, my teeth were rotten but they took it out so now apparently I have perfect teeth. My second time for check-up the experience was good. They talk well, chat well and are friendly. Maybe when they transfer to bigger room (it will be even better). Experience at the dentist was my mouth was numb but no pain." (Male 18 years, Wellness site)

5.3.3 Social Impact Domain

5.3.3.1 Interpersonal Relationships and Social

When asked to comment on the role and support received regarding teeth and mouth issues, the importance of family or peer support became evident among the ALHIV at the Wellness Clinic. Social support was identified and defined as the backing by people around self, regarding teeth and mouth problems.

When responding, one adolescent from the Wellness site referred to his own health status generally but at the same time related the response to the teeth and mouth care support. According to adolescents, family, mostly mothers, were very concerned about the children's wellbeing especially those with chronic conditions from the wellness site.

"Family they remind you when one has forgotten medication, and that is good. My place, we're five people living in our house; they are supportive, they remind me to take my medication for my sickness, they give me stuff when I ask for them. When there no money they don't give me and I understand." (Male 16 years, Wellness site.)

One adolescent acknowledged and appreciated the feedback about mouth problems from various people. He also mentioned that some symptoms such as 'bad breath' could interfere with the interpersonal relationships and affect how they socialise.

"People are important cos they will tell you what to do or not to do. Bad breath can affect how you socialise, in a group, they will see it as 'bad', and you'll end up not going out." (Male 15 years, Wellness site)

One reported that teeth and mouth problems compete with playtime because if you are not in pain, you are afforded the time to socialise more and play more. They also commented on having to 'fix the teeth first,' attending to teeth and mouth problems before the time for fun.

"Pain disturbs because sometimes when you are having a fun time with friends or maybe it's a big thing you need to go to the dentist to fix the problem, sometimes your cousins will have more play time than you." (Female 14 years, School)

5.3.3.2 Self-image and self-awareness

Self-image and awareness covered a continuum of individual and socially acquired perceptions. Self-image reporting was related to acceptance in the society. Acceptance of their current and felt symptoms arose from the adolescents attending the Wellness Clinic. Both female and male adolescents expressed the yearning to be accepted by other peers, with being 'cool' an aspiration expressed by many. The males reported self-confidence as a way of being macho and manly. Males expressed the township nuances of being cool and the associated greatness in the responses.

Acting 'cool' may also have been a coping mechanism, primarily because at the wellness site, routine group counselling occurred at every weekly visit by the resident social worker. The IDIs occurred in a context where group counselling services were offered to the ALHIV to increase compliance with the ARV medication. Counselling services also assisted ALHIV with disclosures about their HIV status.

"I don't care what my friends say or think about me, when it comes to 'ukuhloma'- being cool, I'm doing it for me not for them. But it is different when it comes to girls, imagine...no there is different." (Male 18 years, Wellness site)

More adolescents in the wellness group expressed embarrassment about oral conditions than those recruited from the school site. Females generally were more embarrassed than males, expressing feelings of shyness and anxiety when they had to interact with people around them. Closely linked to that was the element of wanting to isolate themselves and not mix with others due to the problems with their teeth and mouth. "I do get embarrassed when I have gum problems. I am scared to talk this worries me – (rated 5/10). That makes me sad, and I keep quiet, and I stay alone." (Female 16 years, Wellness site)

One female from the Wellness site was distressed and hurt from her oral symptoms of pain, bleeding gums and associated bad breath.

"I hurt (participant really aggrieved when she is relating the story of pain and bleeding gums she was crying) because it shows teeth are not right. I feel bad. I cry because it makes me worry about my condition, [that I am sick] it makes me think about what are they thinking of me." (Female 19 years, Wellness site).

In summary, the responses of the adolescents were based on **i**) their current oral health status, **ii**) their experiences and feelings thereof, **iii**) their perceptions and experiences of oral health care; **iv**) the actions to resolve their oral health status, and finally, v) the impact of their current health and oral health status on their feelings. All were affected by their oral conditions. The intensity and frequency of the conditions varied and was expressed more by the HIV infected adolescents than by their HIV uninfected counterparts.

5.4 DISCUSSION

The in-depth interviews used in the study relied solely on the honest recollection of the study participants of their opinions and views on oral health. Discreet observation of the participants might have captured their experiences and behaviours more accurately as opposed to depending on what they said. Taking into consideration the shortcomings, this study provides an account of OHRQoL perceptions and experiences of adolescents at an HIV Wellness Centre and a group of HIV undiagnosed adolescents recruited through schools in Johannesburg.

The understanding of oral health in both groups was consistent with global definitions of oral health as not mere absence of disease and included the ability to fully function and interact (15). The perceptions and experiences of oral health were noted as interconnected and perpetuated by each other, with the benefit of influencing the adolescents' oral health practices and health seeking behaviours. This observation is in agreement with an existing oral health conceptual framework that demonstrates the effect of oral health perceptions on oral health behaviours and the responsibility to care (89).

The participants, particularly ALHIV, placed a high value on oral health functioning and symptomology. Female participants were more expressive about their felt symptoms and impairments than were the male participants. This was expected as females tend to be more expressive during the adolescent years, with males having less interest in health issues at that stage (92).

A Brazilian study added that females are more sensitive to physical appearance during adolescence compared with their male contemporaries (93). The most common functional impairments cited were impaired ability to chew, talk and inability to brush teeth. This observation is worrying given the high prevalence of oral conditions previously reported among ALHIV (19, 20, 30, 81, 94).

Experiencing oral health symptoms and functional difficulties resulted in the adoption of selfcare and coping practices perceived to be an adequate response to the need. The self-care practices were often adopted to manage pain. This response could, however, delay professional attention and care and could lead to complications (95).

The current study findings are similar to a qualitative study of adults living with HIV in Cape Town, South Africa, where participants relied on home remedies and over-the-counter medications, which delayed oral care (95). However, reliance on home remedies for pain also may be linked to poor access and uptake of health services due to previous bad experiences with using health services or the inability to use health services for other socioeconomic reasons.

Conceptually, access to oral health care is an important determinant both at the individual and family level (26, 89). Access to health services influences oral healthcare-seeking behaviour and, by extension, oral health wellbeing. External structural barriers to access to dental service, such as costs and distance, were evident from the study. Bad dental services experiences, also linked to bad staff attitudes, were associated with the perception that free public dental services are of poor quality.

The deterrent effect of healthcare worker attitudes on the pathways to patient satisfaction is well documented in South Africa (96). Consequently, service access is avoided or delayed, with bad services endured by a resilient few due to their limited choices in service provision for reasons such as affordability of care.

Levels of self-image and awareness, and (self)-stigmatisation were other common themes impacting on the adolescents' perceptions and experiences of OHRQoL. Some participants recounted how halitosis (bad breath) resulted in their social isolation. The self-assigned isolation is a sign of self-stigma noted in the HIV disease and stigma trajectory (97).

This theme was more common among ALHIV due to negative labelling arising from internalised shame associated with the causes of the HIV infection (98, 99). In addition, the attributional process of self-stigmatisation diminishes internalised beliefs about self and consequently the OHRQoL of the ALHIV.

From a theoretical perspective, our findings confirm that both individual and environmental characteristics influence biological functional status, but there is little or no mention of culture and beliefs as determinants of OHRQoL among adolescents in Johannesburg. The theoretical model of oral health-related quality of life proposed by Sischo and Broder (2011) which influenced tool development was supported (26).

This model highlights the multi-dimensional 'outer' individual and environmental characteristics and the 'inner' overall physiological processes (biological function, symptom status and functional status) which together influence the overall status of the OHRQoL (26). The interaction between biomedical and psychosocial dimensions and constructs of OHRQoL is also present in a model proposed in 2005 (33).

In conclusion, the perceptions and experiences of OHRQoL among ALHIV in Johannesburg are driven by a combination of how they viewed themselves and socialised, and the sum of the state of their structural environments and biological wellbeing. This is in agreement with existing OHRQoL frameworks and tools. This study also underscores the high value that ALHIV in Johannesburg place on issues such as coping ability, symptom endurance, resilience and experience of using dental health services.

The study finding can be used to improve the prioritisation and provision of oral health support services for adolescents in Johannesburg, based on the observed service delivery gaps and the value they place on some of the themes identified, while bearing in mind gender differences and preferences. This proposition does not negate the need for further quantitative exploration of the adolescents' ranking of the various themes such as stigma and self-perception, symptom endurance and experience of using health services even in the context of universal HIV

treatment in South Africa. Furthermore, the need to secure enhanced oral health promotion is underscored to discourage the delay in seeking care (95).

Such efforts should include the promotion of preventive measures to improve oral health. Greater integration of oral health services into common adolescents' health services and school health programmes is an imperative (81). The study also re-emphasises the need to intensify general health services re-sensitisation for more adolescent and youth friendliness.

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CHAPTER 6: The burden of oral conditions among adolescents living with HIV at a clinic in Johannesburg, South Africa

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administration	

For the objective three of the research project, it was necessary to establish the amount or /and prevalence of common oral diseases:- dental caries and the oral mucosal lesions among the key study participants., before we can measure the oral-health-related quality of life impacts.

It was essential to ascertain how much disease is present, in addition, to look at the trends in the oral health/disease HIV trajectory. It is necessary to monitor the importance and the significance of the pattern of the oral lesions. In the past before the HIV improved roll out worldwide, HIV –related oral lesions were being used as early markers of infection. Later, during the roll-out periods, HIV –related oral lesions can be used to monitor therapy compliance and adherence. As viral suppression manifests due to good adherence and compliance; a reduction in oral lesions is expected; in addition, as reported in some literature, new type of oral lesions such oral warts may be seen.

The following chapter is a published paper (details below) aimed to report on the epidemiological patterns and trends of the oral disease among ALHIV in a Johannesburg, HIV Wellness Centre.

Abstract:

There are inconsistent reports on the prevalence of oral conditions and their associated factors among adolescents living with HIV (ALHIV). The current inconsistencies may hinder the development of clear guidelines on the prevention and treatment of oral conditions among ALHIV. This study provides an update on oral conditions and their associated factors in a cohort of South African ALHIV and receiving routine HIV treatment services at a Johannesburg HIV wellness clinic.

Methods :Decayed Teeth (DT), Decayed Missing and Filled Teeth (DMFT) and Oral HIV/AIDS Research Alliance case definitions were used for caries examination and reporting of the Oral Mucosal Lesions (OML) respectively. Data analyses were stratified by the study main outcomes; chi-squared tests were performed to determine the associations; and multiple logistic regressions were also used to identify associated factors after adjusting for other exposure variables. In addition to fitting logistic regressions, we explored the data for potential confounders and effect modifiers.

Results : A total of 407 ALHIV were assessed, of which 51.0 % were females. The mean age of the ALHIV was 14.75 years (SD 2.43) while the median age of their parents was 43 years (IQR 37-48 years). Regardless of sex, age group and other socio-demographic characteristics, participants had high count of dental caries (DMFT>0).

The overall prevalence of dental caries was 56.76% (n=231) with mean DT score of 2.0 (SD 2.48) and mean DMFT score of 2.65 (SD 3.01). Dental caries prevalence (DT>0) was significantly associated with the HIV clinical markers. HIV RNA viral loads more than 1000 copies/ml and CD4 cell counts less than 200 count cells/mm3, increased the likelihood of having dental decay among ALHIV (p<0.05). ALHIV at WHO staging III, IV had higher caries prevalence ranging from 70% to 75% (p<0.05). The prevalence of dental caries was directly related to the presence of oral mucosal lesions (p<0.05). The prevalence of OML was 22%, with linear gingival erythema (13.8%) accounting for most of the OML. Multiple logistic regression modelling suggested that dental caries experience (DMFT>0), age category 13-15 years, WHO staging of IV and viral load of more than 1000 copies/ml significantly predicted the outcome of oral lesions as assessed using the OHARA case definitions (p<0.05). The odds of developing dental caries was also 1.5 times more among ALHIV who brush their teeth less frequently and those who reported more frequent eating of sugar sweetened diets (p<0.05).

Conclusions: There is high prevalence of dental caries and OML among ALHIV in Johannesburg. The reported prevalence was associated with high HIV RNA viral loads, shorter duration on antiretroviral treatment and high WHO staging of HIV disease. Additionally, caries experience contributed to the prevalence of OML. Our study acknowledges the protective effect of HIV treatment and positive oral health practices on the presence of oral conditions among ALHIV in Johannesburg.

Keywords: Adolescents, epidemiology, HIV AIDS, oral disease

6.1 INTRODUCTION

The chronicity of HIV infection has been associated with varying patterns and presentations of oral diseases mainly linked to whether the patients were on antiretroviral treatment (ART) or not. For example, the long term use of ART has significantly decreased the presence of opportunistic lesions commonly associated with HIV infection (1, 2). The prevalence of oral conditions has also been attributed to other treatment characteristics such as the regimen(2). In the era before the widespread availability and use of ART, oral lesions were considered as one of the first signs of HIV seropositivity, and an indication of treatment failure and/or poor adherence to ART (3-5). Furthermore, the occurrence and type of lesions before and during ART have also been reported to differ in different settings (2).

Despite the improved and increasing use of ART, oral lesions associated with HIV infection have been reported to continually persist across all age groups among children (5, 6). For instance, research studies in India and Uganda have reported over 60% prevalence of orofacial manifestations associated with HIV among children and adolescents who were on ART[(7, 8). Common lesion identified among ALHIV include ulcers, warts, carcinoma and salivary gland conditions (2). This trend is a source of concern for South Africa, because the country maintains the highest number of people living with HIV (PLHIV) globally, including its approximately 370 000 adolescents aged between 10 and 19 years old, living with the virus (9). This sub-population is key in this paper and, will be referred to as adolescents living with HIV (ALHIV).

Managing ALHIV on ART presents extra challenges which may influence the occurrence of oral lesions. For example, the disclosure of HIV status to perinatal HIV infected adolescents may present additional mental health implication and effects. This is given the mean age of disclosure in South Africa to be at about 10 years of age(10). In addition, treatment fatigue (11) and depression(12) are some of the challenges experienced ALHIV. These factors are known to influence adherence to treatment (13). Further research suggests that poor treatment adherence among ALHIV, increases the risk of developing caries, periodontal disease and halitosis (4, 14). Other studies have shown that the use of sugary medicine (syrups) and sugar sweetened diets presents additional risks to oral conditions (15, 16).Other risk factors for oral conditions among adolescents includes poor oral hygiene, social and demographic barriers, periodontal diseases and irregular access to dental services (6, 7, 17).

An epidemiological update of oral conditions among ALHIV, especially in contexts with elevated HIV prevalence, such as South Africa is imperative given the variations in risks factors and prevalence of oral conditions among ALHIV. The goal of this study was to determine the burden of oral disease and their associated factors among ALHIV who are on ART treatment and attending routine HIV treatment and care at a public HIV wellness clinic in Johannesburg, South Africa. In this regard, the presence of oral condition was measured using the Decayed, Missing and Filled Teeth (DMFT) index (18) and the Oral HIV/AIDS Research Alliance (OHARA) case definitions were used to record the oral mucosal conditions (19).

6.2 METHODS

6.2.1Design and Study Participants

We conducted a cross sectional study to determine the burden of oral conditions among ALHIV. The study was conducted among ALHIV aged 10–19 years, on ART and accessing routine HIV treatment, care and support services at a HIV wellness centre in Johannesburg, South Africa. The catchment population is made up of inhabitants of the Greater Johannesburg Metropolitan Area. Twenty-one percent of inhabitants in this province are living with HIV (20).

6.2.2 Sampling

A sample size of 400 participants was calculated. The sample size was based on the assumption that if approximately a quarter (25%) of the participants will have a controlled viral load /virological control (viral load less than 40 copies/ml), then this sample size will have 87% power to detect as statistically significant an absolute difference of 15% in the proportion of participants with oral lesions. The above assumes that among the participants with virological control, 15% have oral lesions. So, among participants without the viral load control, 30% have oral lesions. The inclusion criteria was: Those who were 14–19 years and voluntarily provided written assent and consent to the study. Parental consent for those aged 14–17 years of age. Participants should be part of the HIV wellness centre with confirmed HIV diagnosis and have been initiated on ART. Adolescents aged between 18–19 years did not require parental consent because they were eligible to provide their own written consent. Eventually 415 participants attending the HIV Wellness Clinic were recruited.

6.2.3 Data Collection and Data Analysis

Study participants were recruited from the HIV wellness clinic. The participants were approached about the oral health study by the administrative staff at the clinic. During the oral health care routine consultations, potential participants and their caregivers were informed about the details of the study. Those who provided informed consent or/and assent were enrolled as research participants. Recruitment process took approximately nine months, until the estimated sample size was achieved. Eight out of 415 did not agree to participate in the study due to other commitments (not having time for questionnaire and examination due to personal commitments for participants or the parent/caregiver). Information on their socio-demographic characteristics and detailed oral health history were collected. Details of oral-health-related complaints, oral hygiene habits, and general oral health were collected from participants.

Dental examinations were performed by two calibrated dental practitioners. Reports on clinical characteristics such CD4 count, viral load and WHO HIV clinical staging were obtained from participants' medical records. These variables constitute the clinical markers of HIV disease in our study. A dental clinical examination based on Decayed Missing and Filled Teeth (DMFT) index as outlined in the primary survey methods by the World Health Organization was also performed (18). The DMFT index determined the presence of dental caries and treatment needs. Patients were examined while sitting in the supine position on a portable dental chair using artificial light in the clinic. The Oral HIV/AIDS Research Alliance (OHARA) case definitions were used to record the oral mucosal conditions (19). Clinicians were trained using the training material slides based on the 2009 Oral HIV/AIDS Research Alliance (OHARA) recommendation [19]; the score for correctly diagnosed conditions had to be 80% and above in order to proceed with data collection. The inter-examiner reliability was done by reexamining one tenth of the sample by each examiner, and the calculated kappa statistics was 0.81 for DMFT, and 0.87 for OHARA case definitions. All statistical analyses were performed using Stata version 14 (StataCorp, College Station, Tx). In the descriptive analysis sociodemographic, oral and clinical characteristics - which were all categorical variables, were summarised using proportions. All analyses were stratified based on the outcome variables of interest: DMFT (caries experience), DT (dental caries) and OHARA (Oral mucosal lesions). Chi-squared tests were performed for associations.

We also calculated the Significant Caries Index (Sic) which brings to focus the individuals with the highest caries scores (D) in each population under study. The Sic Index is calculated by selecting one third of the population with the highest DMFT scores. The mean DMFT for this subgroup is calculated. According to the WHO, this Sic Index value provides information on individuals at highest risk and this value should be targeted to be three or less (21). Multiple logistic regression analyses were also used to identify associated factors after adjusting for other exposure variables.

Using backward and forward stepwise elimination exposure, variables that had a p-value <0.1 in there crude bivariate regression analyses were included in the multivariate logistic regression modelling were used. In addition to fitting logistic regressions, we also explored the data for potential confounders and effect modifiers. For inferences, the significance level was set at 5%. This study received ethical clearance [Ref. number: M161142] from the Human Research Ethics Committee of the University of Witwatersrand, Johannesburg.

6.3 RESULTS

6.3.1 Socio-demographic Characteristics And Caries Experienced

A total of 407 ALHIV were assessed, of these 51.0% ALHIV were females and 49% males. The participants' median age was 15 years (IQR 13–15) while the age of the parents/caregivers was 43 years old (IQR 37–48). Most of the parents/caregivers were females (78.3%), employed (60.3%), with a secondary school level of education (67.3%). Most of the participants came from families whose household size was composed of four to six people (52.9%). As shown in Table 6.1; regardless of sex, age group and other socio-demographic characteristics, adolescents had high counts of dental caries (DMFT>0).

Table 6.1. Socio-demographic characteristics of participants with or without cari	es
experience.	

Characteristics		Caries experience (DMFT)		
	Sample size(n) ^{\dagger}	DMFT=0; - n	DMFT>0; n (%)	
		(%)		
Adolescents' sex				
Male	196	74(38.14)	120(61.86)	
Female	204	75(37.63)	127(62.87)	
Adolescents' Age Group				
10-12years	84	38(45.24)	46(54.70)	

13-18 years	158	45(28.48)	113(71.52)
16-18 years	154	64(41.56)	90(58.44)
Adolescents' Education			
Primary	137	51(37.23)	86(62.77)
Secondary /Tertiary	237	90(37.97)	147(62.03)
Special School	4	0(0)	4(100)
Parents'/caregivers' Sex			
Male	83	29(35.37)	53(64.63)
Female	300	115(38.72)	182(61.28)
Parents'/caregivers' Age			
group			
18-30yrs	23	5(22.73)	17(77.27)
31-40yrs	116	39(33.62)	77(66.38)
41-50yrs	154	63(41.18)	90(58.82)
51-60yrs	44	21(48.84)	22(51.16)
> 60yrs	21	4(19.05)	17(80.95)
Parents'/caregivers'			
Employment status			
Employed	211	65(31.40)	142(68.60)
Unemployed	131	56(42.75)	75(57.25)
Retired	8	4(50)	4(50)
Parents'/caregivers'			
Education			
Tertiary	77	34(44.16)	43(55.84)
Secondary school	239	86(36.29)	151(63.71)
Primary school	39	15(38.46)	24(61.54)
Household size			
1-3 persons	125	40(32.52)	83(67.48)
4-6 people	201	77(38.50)	123(61.50)
>7 People	54	24(45.28)	29(54.72)
† Missing values not included in	the totals		

6.3.2 Dental Caries

Dental Caries Prevalence and HIV Clinical Markers.

Out of the 407 ALHIV in our study, the caries prevalence was 56.76% (n = 231) with mean 'D' (decayed teeth) score of 2.0 (\pm SD 2.48) and caries experience mean DMFT score of 2.65(\pm SD 3.01). This means the dental caries component ('D-decayed' 2.0) was the major contributor (77%) to the total DMFT score (2.6).

The Sic value for the participants was found to be 4.90 (SD = 2.10) which implies that the distribution of dental caries in this study cohort was unevenly skewed towards a third of the individuals in the sample. Table 6.2 also presents prevalence and association between dental caries and the clinical markers of HIV disease (including CD4 counts, viral load and the WHO clinical staging of the disease). ALHIV with oral mucosal lesions had higher dental caries compared to those without OML (73% vs 52%, p <0.001). All HIV clinical markers were associated with dental caries. The prevalence of dental caries was higher among those with lower CD4 cell counts (p <0.001). Higher HIV RNA viral loads levels had higher prevalence of dental caries compared to lower HIV RNA viral loads levels (p <0.05).

Table 6.2. HIV clinical markers in ALHIV with and without dental caries

Characteristic	Dental Caries pro	evalence	†p-value	
Caries Experience	DT=0 (n=176) Frequency (%)	DT>0 (n=231) Frequency (%)		
DMFT=0	150(100)	0	< 0.001***	
DMFT>0	26(10.12)	231(89.88)		
CD4 count				
<200CD4 cells/mm ³	13(30.95)	29(69.05)	0.01**	
200-500CD4 cells/mm ³	30(33.33)	60(66.67)		
>500CD4 cells/mm ³	127(48.29)	136(51.61)		
Viral Load				
<40VL copies/ml	62(48.00)	67(51.94)	0.02*	
40-1000VL copies/ml	99(44.00)	126(56.00)		
>1000VL copies/ml	12(25.00)	36(75.00)		
YEARS ON ART				
0-4 years	18(25.00)	54(75.00)	< 0.001***	
5-9 years	60(37.50)	100(62.50)		
≥ 10 years	98(56.00)	77(44.00)		
Oral mucosal lesions				
OHARA =0	152(47.65)	167(52.35)	< 0.001***	
OHARA >0 ^a	24(27.27)	64(72.73)		
WHO HIV STAGING				
Ι	113(52.80)	101(47.20)	< 0.001***	
Ш	15(39.47)	23(60.53)		
III	19(29.69)	45(70.31)		
IV	19(25.33)	56(74.67)		

OHARA>0^a referred to at least one lesion diagnosed.

† Based on Pearson chi-squared tests and Fischer Exact for cells <5;

* $p \le 0.05$, ** p < 0.01, *** p < 0.001

Similarly, the higher the WHO staging (Stages III, IV), the higher the caries prevalence (ranging from 70% to 75%) (p<0.05). There was an inverse relationship between dental caries and duration on ART. A decrease in the dental caries prevalence was associated with the increase in the duration on ART from 75% to 44% in decrease (p<0.001) (Table 6.2). Unadjusted logistic regression shown in Table 6.3 indicated that HIV RNA viral loads greater than 1000 copies/ml, WHO stage III and IV, increased the odds of dental caries by more than 2.5 times, than viral undetectable loads and WHO Stage I and II respectively. In contrast, CD4 count cells/mm3 of more than 500, a longer duration on ART of more than 10 years reduced the odds of dental decay (OR:0.480[0.239,0.964] and 0.262[OR: 0.142,0.483])(Table 6.3). However, after adjusting for confounders, only the HIV clinical marker of HIV RNA viral loads more than 1000 copies/ml influenced the odds of dental caries in Table 6.3. Sex of adolescent, parents' age group or level of education were not associated with presence of oral conditions.

III	19(29.69)		45(70.31)			
	Unadjusted OR (CI)	Adjusted OR (CI)	Unadjusted OR (CI)	Adjusted OR(CI)		
Viral Load copies/ml						
<40	Reference	Reference	Reference	Reference		
40-1000	1.21[0.79,1.88]	1.24[0.58,2.65]	1.42[0.81,2.49]	1.42[0.80,2.55]		
>1000	2.54**[1.28,5.06]	1.07[0.26,4.43]	2.37*[1.15,4.92]	2.94*[1.25,6.92]		
CD four counts cell/m ³						
<200CD4	Reference	Reference	Reference	Reference		
200-500CD4	0.90[0.41,1.97]	1.39[0.34,5.77]	1.01[0.43,2.37]	1.11[0.44,2.83]		
>500CD4	0.48*[0.24,0.96]	0.52[0.15,1.78]	0.82[0.38,1.78]	1.06[0.44,2.56]		
WHO staging						
Ι	Reference	Reference	Reference	Reference		

Table 6.3. Factor associated with d	ental caries and o	ral mucosal lesion	s among
adolescents living with HIV.			

II	1.72[0.85,3.47]	1.30[0.36,4.65]	1.56[0.74,3.33]	1.34[0.58,3.01]
III	2.650**[1.46,4.83]	1.79[0.70,4.60]	0.95[0.48,1.86]	1.03[0.51,2.09]
IV	3.30***[1.84,5.92]	3.93**[1.47,10.50]	0.62[0.31,1.23]	0.55[0.26,1.17]
ALHIV age group				
10-12 yrs	Reference	Reference	Reference	Reference
13-15 yrs	1.69[0.99,2.89]	0.63[0.22,1.81]	1.16[0.60,2.26]	0.83[0.41,1.66]
16-18 yrs	1.06[0.62,1.81]	0.29*[0.09,0.88]	1.35[0.70,2.61]	1.02[0.49,2.11]
ALHIV Education level				
Primary	Reference	Reference	Reference	
Secondary/Tertiary	0.87[0.56,1.33]		1.34[0.79,2.29]	
Special School			14.12*[1.408,141.7]	
Years on ART				
0-4 yrs	Reference		Reference	
5-9 yrs	0.56[0.30,1.04]		2.59*[1.19,5.65]	
>=10 yrs	0.26***[0.14,0.48)		1.94[0.88,4.25]	
Caries Experience				
DMFT=0			Reference	
DMFT>0			3.03***[1.71,5.38]	
Parents Sex				
Male	Reference	Reference	Reference	
Female	0.90[0.55,1.478]	0.41*[0.18,0.92]	0.98[0.54,1.77]	
Parents Employment Status				
Unemployed	Reference	Reference	Reference	
Employed	1.60*[1.03,2.50]	2.85**[1.33,6.19]	1.54[0.88,2.72]	
Retired	0.99[0.24,4.11]		5.24*[1.21,22.61]	
Satisfaction with Oral Health				
Disagree	Reference	Reference	Reference	
Undecided	1.03[0.67,1.59]	1.42[0.63,3.23]	1.03[0.62,1.70]	
Agree	0.37**[0.19,0.73]	1.09[0.29,3.95]	0.63[0.26,1.51]	

Self-rated oral				
health				
Poor-fair	Reference	Reference	Reference	
Good	0.46***[0.29,0.71]	0.692[0.30,1.60]	1.17[0.72,1.90]	
Very good- Excellent	0.13***[0.064,0.26]	0.17**[0.05,0.62]	0.20**[0.06,0.66]	
Soft drinks ingestion				
Weekly	Reference	Reference	Reference	
Daily	1.51*[1.01,2.26]	1.71[0.82,3.55]	1.17[0.71,1.91]	
Frequency of eating sweets				
Weekly	Reference		Reference	
Daily	1.51*[1.01,2.26]		1.17[0.71,1.91]	
Tooth brushing frequency				
Twice daily	Reference	Reference	Reference	
Once daily	1.54*[1.03,2.31]	1.73[0.82,3.62]	1.09[0.67,1.77]	

OHARA>0^a referred to at least one lesion diagnosed.

Exponentiated coefficients; 95% confidence intervals in brackets

* *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001, [‡] Marginally significant *p* < 0.1

Dental Caries and Behavioural Traits

Bivariate analysis between dental caries experience and behavioural characteristics showed significant association particularly with self-perceived dental treatment need (p<0.05); self-rated oral health (p<0.01); oral hygiene habits (p<0.05) and sugary diets (p<0.05) as presented in Table 6.4. The results suggest that those with good oral hygiene behavioural habits were associated with less dental caries occurrence. Unadjusted logistic regression in Table 6.3, indicated that those who self-rated their oral health to be good/very, good/excellent were less likely to have dental decay (OR: 0.46[0.292, 0.709] and OR: 0.13[0.0636, 0.259) respectively compared to those who rated themselves poor-fair. Frequency of tooth brushing also determined the occurrence of dental caries. The odds of developing dental caries were 1.5 times more among those who reported to less frequent tooth brushing than those who brushed twice daily (OR: 1.542 [1.031,2.305]). The odds of having dental caries were 1.5 more for those with daily consumption of sugar sweetened diets than those with weekly consumption.

After adjusting for confounders, only self-rating was likely to be associated with dental caries (OR: 0.1680.0459, 0.616).

Table	6.4.	The	behavioural	characteristics	and	self-rating	of	adolescents	and	the
associa	tion	with	untreated car	ies prevalence						

Behavioural characteristics	DT=0(%)	DT>0 ^{<i>a</i>} (%)	†p-value
General self-rating of teeth and			
mouth			
Poor-fair	51(29.31)	123(70.69)	< 0.001
Good	82(47.67)	90(52.33)	
Excellent	42(76.36)	13(23.64)	
Satisfaction with tooth and mouth condition?			
Disagree	73(40.11)	109(59.89)	0.01*
Undecided	65(39.39)	100(60.61)	
Agree	29(64.44)	16(35.56)	
Need dental Treatment?			
Disagree	55(46.61)	63(53.39)	0.05*
Undecided	35(55.66)	28(44.44)	
Agree	86(38.91)	135(61.09)	
Tooth brushing Frequency			
Once a day	94(48.21)	101(51.79)	0.04*
Twice a day	75(37.88)	123(62.12)	
Soft drinks consumption frequency			
Sweet drinks=Weekly	84(48.28)	90(51.72)	0.05*
Sweets drinks=Daily	83(38.25)	134(61.75)	
Sweets consumption Frequency			
Sweets =Weekly	84(48.28)	90(51.72)	0.05*
Sweets =Daily	83(38.25)	134(61.75)	
Total	42.71%	57.29%	

DT>0^a referred to at least one caries lesion diagnosed.

* $p \le 0.05$,

† Based on Pearson chi-squared tests.
6.3.3 Oral Mucosal Lesions

Oral mucosal lesions (OML) and HIV clinical markers. About 21.2% of the participants had a type of oral mucosal lesions. Fig 6.1 shows linear gingival erythema (LGE) to be the most commonly diagnosed OML (13.8%), followed by necrotising gingivitis (2.2%) and pseudomembranous candidiasis (1.7%). Other lesions that were diagnosed included herpes labialis n = 4, angular cheilitis n = 3, ulceration not specified and oral warts each n = 2.





Oral Mucosal Conditions and Behavioural Traits.

Results of the unadjusted logistic regression analysis suggested that dental caries experience (DMFT>0), viral load of more than 1000 copies/ml and self-rated oral health that is 'very good-Excellent' affected the odds of oral mucosal lesions (OHARA>0) appearance (Table 6.3). After adjusting for socio-demographic, behavioural and clinical markers confounding; only HIV

RNA viral loads of more than 1000 copies/ml increased the odds of oral mucosal lesions occurrence nearly three times (OR: 2.935) [1.245,6.920]).

6.4 DISCUSSION

We found 57% prevalence of dental caries among ALHIV on ART. The prevalence of dental caries in our study population is higher than the earlier reported 30% and 42% national dental caries prevalence among 12 and 15 year old respectively in the general population (22). Our find is however similar to the 61% dental caries prevalence found among a similar American cohort of ALHIV on ART(6). Furthermore, the untreated mean DT score of 2.2 in the American study is comparable to our study's DT score of 2.0 where DT contributed 77% to the total DMFT.

The latter implies the factors such as attitudes towards dental decay (presence of disease but adolescents wait for symptoms to develop before accessing care) or dental access (adolescents are aware of decayed teeth in the mouth but access to treatment might be a challenge) maybe similar in the two settings.

In consonance with our findings, the high prevalence of active dental caries among ALHIV on ART has also been attributed to the sugar sweetened diets and other socioeconomic characteristics (6, 17). Elsewhere, authors have further purported that dental caries maybe related to xerostomia that is induced by the use of ART (4, 14). Dios and Scully (2014) add that xerostomia is associated with the nucleoside reverse transcriptase inhibitor based ART regimen (4). The socio-behavioural, clinical, treatment needs, and access related correlates and distribution of dental caries found in our study suggest multi-factorial causes of dental caries and the need for multi-level prevention and treatment interventions. It is evident that the factors that put patients at higher risk to caries in general non-HIV-patients also apply to this HIV positive cohort and should not be ignored. This position is validated by studies that have found socioeconomic factors and oral health behavioural characteristics to be strong predictors of the presence of dental caries among adolescents (23, 24).

Our observation of higher prevalence of dental caries among adolescents with younger working parents with the household size of one to three people, may be indicative of the effect of income and social support on the presence of caries among ALHIV. This finding re-emphasises the need for multi-level prevention and treatment interventions including school oral health programmes, restriction of marketing or vendors selling sugary diets especially within school premises and improvement on access to oral health care for ALHIV.

ALHIV with advanced HIV disease based on WHO clinical staging of HIV disease and high HIV RNA viral loads, were more likely to have dental caries in the current study. In addition, longer HIV treatment duration may have had a protective effect against dental caries.

These findings parallel other studies that have found correlations between dental caries and ALHIV immunological profile (25). Similarly, Beena (2011) found that the dental caries worsened with the deterioration of children's immune-competence evidenced by high HIV RNA viral loads (26).

We also found caries prevalence to be inversely related to regular dental access, good oral health self-rating, and regular brushing of teeth. In our analyses, infrequent brushing of teeth seems to increase the likelihood of having dental caries. Our results therefore support and add to the current evidence that good oral hygienic habits and regular access to dental care have the potential to improve the caries status among ALHIV. In further concordance with our results, poor oral hygiene (including high consumption of sugary drinks and sweets) and poor use to oral health services are well documented risk factors for dental caries particularly among ALHIV (6, 7, 17).

The OML prevalence in our study is higher than what has been previously reported among similar age cohorts on antiretroviral treatment. A study by da Silva et al., (2008) in Brazil (27) and Moscicki et al. (2016) in the United States of America (6) found the lowest prevalence of OML at <1% while Meless et al. (2014) in West Africa (Mali, Senegal, Ivory Coast) (28) found a prevalence of 8.5%. At least one lesion found in every five ALHIV in our study is not a negligible prevalence and efforts to reduce the OML must continue in our study setting.

Frequent screening, early diagnosis and effective management are essential to prevent the progression of symptoms of LGE to a severe form of gingivitis which might result in pain, halitosis and other negative psychosocial and mental consequences such as stigma, shaming or depression (29).

The factors contributing to the presence of OML also varied in many studies. Review papers aimed at providing an update on children and adolescents oral lesions in HIV/AIDS in low and middle income countries, found that the prevalence of OML could vary with diagnostic

methods, duration on treatment and treatment regimens (2, 7, 30). Similarly, we found an association between the presence of OML and the duration on ART, where the longer duration meant less OMLs. Other studies found a correlation of OML with CD4 cell counts <350 cells/mm3 (27, 28) in contrast to the current where only high HIV RNA viral loads more than 1000 copies/ml were significantly associated with OML after adjusting for confounding.

Behavioural traits such as frequent intake of sugary diet and poor oral hygiene habits including infrequent tooth brushing were also found to be directly related to dental caries in the crude analyses but not with OML in the present study. Only good self-rating of oral health was inversely linked to OML. Previous studies have found a correlation of OML with poor oral hygiene (7, 28). Poor oral hygiene was also related to minimal dental access and poor socioeconomic status in the study conducted in Uganda; and has the potential to favour and breed pathogens such as candida spp (28).

The role of ART on OML is a positive one as shown in various literature and in our current study by a lesser prevalence of the lesions (1, 6, 31). This study also found out that OML such as necrotising ulcerative gingivitis is rare, while OMLs such as ulcers (4–16%) and linear gingival erythema (2–9%) are more common in ALHIV. Gaita'n-Cepeda et al., (2015) found that candidiasis is still prevalent despite ART and it is the highest in African cohorts, followed by Indian cohorts and is lowest in American cohorts (2.9%)(31).

Our study acknowledges the protective effect of HIV treatment and healthy oral hygiene practices on the presence of oral conditions. Consequently, the need to promote treatment adherence and positive oral health behaviour among ALHIV in South Africa is imperative. The distribution of dental caries by socio-demographic characteristics will require further exploration. In all, the correlates of oral conditions identified in this study present at multi-levels and may warrant greater multi-level integration of oral health services into existing adolescents' HIV treatment, support and care services to better identify and reduce untreated oral conditions.

6.5 LIMITATIONS

This study is not without limitations. While this was a cross sectional survey, it does not indicate if the reported oral conditions are acute or recurrent. Yet, our findings highlight the decreasing but present burden of oral conditions among ALHIV despite their access to HIV

treatment, care and support. The reporting of oral health behaviour was self-reported by the participants through an interview with the examiners and may have introduced social desirability and reporting bias. However, the observed associations between the oral health self-report and objective measurements of oral health status gives credibility to the self-reports.

Lastly, the reports about the current study should take into cognizance that there was a time lag between the oral examination and or diagnosis of the oral mucosal lesions and dental caries with the HIV blood markers such as HIV RNA viral loads and CD4 counts recorded on the participants' records of about three weeks.

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CHAPTER 7: Validation of the Modified Child Oral Health Impact Profile (COHIP) Among HIV infected and HIV undiagnosed Adolescents in Johannesburg, South Africa-Comparative study

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This final chapter of the study project culminated with a measurement of oral-health-related quality of life of the adolescents in the research sites. This is following the initial study phases where the information related to modifying the tool was explored, gathered, and analysed into themes arising from the Johannesburg setting. The original OHRQoL for the children was thus modified based on the three broad themes from the early qualitative study. The premise for the whole study was in order to measure the OHRQoL outcomes of the adolescents in the setting. Therefore, socially and contextually sensitive tools were necessary to assess OHRQoL in the SA, Johannesburg context accurately. It is advisable that before a measurement tool is used for the first time in a different context or type of participants, it should be validated and tested for applicability to that context. The reasoning behind the latter is that context, environment, individual experiences and socialisation influence how health is perceived as noted by many scholars such as Herdman, Beaton et al., Traebert et al. and Barbosa and Gaviao (1-4) and by

the OHRQoL conceptual framework (5). The health perceptions shape how oral-health-related quality of life is expressed and experienced by individuals. The chapter also, after testing the tool for validity, reports on the factors that influenced OHRQoL in the adolescent participants in the Johannesburg setting.

Abstract:

Introduction: Oral health-related quality of life (OHRQoL) is described as the effect of oral conditions on the overall functioning and wellbeing of individuals. Thus, OHRQoL outcomes can impact on daily activities of adolescents.

Aim: This study sought to ascertain the validity and psychometric properties of a modified measure of OHRQoL of HIV infected and HIV undiagnosed adolescents; test the psychometric properties of the modified COHIP (M-COHIP) tool; and, establish the determinants of OHRQoL among adolescents in Johannesburg.

Methods: A cross-sectional study design involving adolescents living with HIV infection (ALHIV) and adolescents attending public schools was conducted. An interviewer-administered modified- COHIP-29 questionnaire was utilised, followed by an oral examination for hard and soft tissue caries and, a review of the medical records.

Results: A total of 504 adolescents (HIV Wellness site n=226 and School site= 278) were included in the study. The overall mean decayed teeth for permanent dentition was 1.6(SD 1.99) and caries prevalence was 62.2 % (n=309) among all adolescents. The tool's overall Cronbach's alpha was 0.88. The item-rest correlations ranged from 0.6 to 0.85 for all items. The initial exploratory factor analysis done on all items explained 76% of the total variance. A total of five components/factors were identified, and these encompassed the 'new' sub-scales. The final confirmatory factor analysis model had two latent factors, namely , the individual and external level factors consisting of eight subscales. The overall M-COHIP score was 59.6(18.2).

The overall modified COHIP/OHRQoL scores of the school group were higher [62.88] than those of ALHIV [55.54]. The poor M-COHIP scores were associated with reporting toothache, having active decay, poor oral health-self-rating, and being selected from the school site (p<0.005).

Conclusion: The M-COHIP displayed acceptable initial reliability and validity. The tool was related to the conceptual framework of oral health-related quality of life. The adolescents' OHRQoL scores were related to the high-untreated caries, toothache reports, a poor self-rated oral health and being in schools. We recommend further studies to test the new sub-scales. **Keywords**: Oral health-related quality of life, Adolescents, HIV

7.1 BACKGROUND

Locker and Allen describe oral health-related quality of life (OHRQoL) as the effect of oral conditions on the overall functioning and wellbeing of individuals (6). Thus, OHRQoL is related to how people grow, look, speak, taste their food, socialise, and their perceptions of social wellbeing (7). OHRQoL outcomes can impact on daily activities of adolescents (6). These activities are essential elements of the formative years of adolescents. According to Barbosa and Gaviao (2008), the conceptualisation of OHRQoL is context-reliant as it highlights relationships on social spheres (4).

Therefore, socially and contextually responsive tools are required to assess OHRQoL in the South African context accurately. Existing OHRQoL measurement tools have a different theoretical basis and, the fact that none have been developed in the African setting complicates the problem.

Notwithstanding the translation and adaptation of the tools, children in different geographical regions of the world have responded differently to the social and emotional wellbeing constructs of OHRQoL assessment instruments (8-12). The difference can be explained by the embedded sociocultural influences (4). The adolescents' sociocultural constructs and nature of symptoms have a bearing on how they conceptualise and perceive health (4, 13).

As of 2018, Eastern and Southern Africa region was home to more than 60 per cent of children and adolescents living with HIV. Numerically, the adolescents living with HIV infection (ALHIV) in the age range of 10 to 19 years old, constituted about 1.6 million of all people living with HIV. South Africa carries the highest burden of ALHIV and accounts for about 310 000 of the global burden(14). In South Africa, 90% of the population know their HIV status, 68% are on treatment, and 87% are virally suppressed(15).

In 2017, one of nine provinces in South Africa, Gauteng Province (where city of Johannesburg lies) had the HIV prevalence of 17.7%. Among the gains of the maternal antiretroviral treatment are the improved treatment coverage, and children with HIV living beyond the adolescent age(16). Antiretroviral treatment is reported to have prevented 1.6 million new HIV infections among children since 2000(17). Consequently, vertically infected youth aged 10 to 19 years old are now emerging as a special population(18). The antiretroviral treatment (ART)

interventions are successful and have increased the life expectancy of South Africans from 56 years in 2010 to 64 years in 2018(19).

The ALHIV and young people in South Africa are most likely to bear a significant burden of the infection despite the growing ART coverage. One in three of the new infections occur among people aged 15 to 25 years old, and the odds of infections are three to five times more likely among females in this age group. Despite the risk, ALHIV today have higher treatment coverage and longer life spans.

The adolescent phase of life involves a transition from childhood to adulthood. This transition is generally characterised by a myriad of physical, emotional, psychological and human developmental changes in all adolescents. Adolescents generally have additional problems related to transitioning in different aspects of life stages, and those infected, their HIV infection status may exacerbate these problems. The added problems include loss of parents and other relatives(20), the onset of puberty(21), disclosure, treatment adherence, HIV stigma issues (22), and negotiating other intimate relationships and identity (23).

Health changes and health concerns may also be unique to this phase in life - specifically, oral health which is an integral part of overall health and wellbeing(24). Thus, the oral health of an adolescent is essential. By and large, the literature on adolescent oral health underscores the increasing dental caries burden and higher oral health needs (25). The increased burden is attributed to susceptibility to environmental factors such as diet, independence to seek care, compliance to care, lifestyle and experimentation, low priority for oral hygiene, self-image concerns and social acceptance (26-28). It is common for the late tooth eruption, development and mixed dentition phase to render most adolescents predisposed to a high prevalence of malocclusion problems (29, 30). Additionally, the burden of oral diseases is likely to be complicated by socioeconomic factors such as poor access to health and preventive dental care (31, 32). Conversely, data from high-income countries report a decline in the caries burden due in part to increased public health measures such as effective use of fluorides (25).

The adolescent phase has numerous life changes and challenges besides the added considerations of living with the HIV infection among adolescents (ALHIV). Thus,

adolescents' OHRQoL measurement is essential in the emergent population of ALHIV. The ALHIV population is a major focus of dental public health due to the oral disease burden. In the sample of HIV infected children, socio-demographic, clinical and behavioural factors were linked to a poorer OHRQoL in the Brazilian study. (33) The burden of oral diseases in HIV infection is exacerbated by factors such as poor access to medical, preventive dental care and limited availability of the protective fluoridated toothpaste to safeguard against sugary medicine (31, 32).

Other risk factors for oral conditions among ALHIV may be poor oral hygiene, social and demographic barriers, and periodontal diseases (34-36). The effects of oral conditions on the OHRQoL of HIV infected children and adolescents are well documented in different parts of the world except in South Africa. The studies conducted outside South Africa reported poorer OHRQoL levels as high as almost 70% (33, 37-40). This may or may not be the case for South Africa, considering that quality of life varies with sociocultural and economic influences (4, 41).

Koot (2001) further suggests that a stage in one's life does influence health-related quality of life (13). In African settings, adolescents and those infected with HIV have been marginally investigated in the broad field of oral health-related quality of life (42). Consequently, adolescents' oral disease experience and the resultant state of OHRQoL needs to be understood. The adolescents' subjective inputs should be included in treatment protocols so that the impacts on their OHRQoL are addressed as part of their overall integrated health care and wellbeing. Risk-based regular monitoring is required for HIV infected adolescents in order to identify their special needs (34). Indeed, several literature recommend moving towards a multidisciplinary and integrated patient-based care of HIV infected children to ensure better outcomes and improved general wellbeing (32, 34, 36).

The OHRQoL outcomes should be measured to ascertain whether they have a significant economic burden on individuals and their families (43). Moreover, OHRQoL measures have been used to access oral health needs (44). This information is important for health service planning and public health policy, especially for this vulnerable ALHIV group.

The Child Oral Health Impact Profile (COHIP) instrument, developed by Broder et al., in United States of America (USA) is an OHRQoL measure incorporating both negative and positive health impacts (45). It has 19 items with five dimensions: oral health, functional wellbeing, socio-emotional wellbeing, school performance and self-image. The current study added ten items under dental care access, coping theme, which arose from the initial qualitative inquiry (46). This study, therefore, seeks to ascertain the validity of this modified measure of the oral-health-related quality of life of HIV infected and HIV undiagnosed adolescents, and thus, test the psychometric properties of the COHIP tool modified for the South African setting.

7.2 MATERIAL AND METHODS

7.2.1 Study Design, Study Participants and Sampling Procedures

A cross-sectional study design involving ALHIV from the HIV Wellness centre at a tertiary academic hospital in Johannesburg, and adolescents attending public schools serviced by the university community project, in inner city Johannesburg was conducted. Two groups of adolescents were recruited for comparative purposes. The groups consisted of HIV positive adolescents and HIV undiagnosed adolescents. As a comparator group, the HIV undiagnosed adolescents were recruited from the two schools in the central business district of the Greater Johannesburg Metropolitan community . The HIV infected adolescents were enrolled from the HIV Wellness site at the Paediatric Virology Clinic within Charlotte Maxeke Johannesburg Academic Hospital (CMJAH).

Sample size

The study consisted of 502 adolescents from two sites (the wellness centre and the schools, respectively). The sample size was calculated by assuming the error margin of 5%, with a 95% confidence interval and from a population of with 400 adolescent learners. Study sample size calculation suggested 280 randomly selected school learners as a comparator group. The ALHIV group (226) was recruited from the HIV Wellness centre in the Academic hospital following proper, informed consent and assent for both groups.

School Participants

Participants from the two public schools within the university's community outreach project were randomly sampled from a sampling frame of learners in Grades 7 - 12, aged 11 to 20 years. With 400 learners in the said Grades, 280 learners were invited. Random computer-generated numbers were created to select the required learners as per the sample size.

The exclusion criteria for the school participants were all adolescents who reported medical history, those on chronic medication, and those without parental consent forms and learners' assent forms. These participants were not tested for HIV and thus were considered HIV undiagnosed.

HIV Wellness Site participants

Similarly, the sample of 226 HIV infected participants was recruited from the HIV Wellness Centre. The participants were patients who came in for their routine wellness services at the centre, which included oral health care. All adolescents, with written informed assent and parental consent for the study, were eligible to be participants. The study received ethical approval from the Human Research Ethics Committee of the University of Witwatersrand, no. M161142. In total, 502 adolescents formed the final sample of the 506 targeted adolescents.

Data Collection

The ALHIV were recruited from the HIV wellness clinic. The participants were approached about the oral health study by the administrative staff at the clinic. During the oral health care routine consultations, potential participants and their caregivers were informed about the details of the study. Those who provided informed consent or/and assent were enrolled as research participants. Recruitment process took approximately nine months, until the estimated sample size was achieved.

Dental examinations were performed by two calibrated dental practitioners. A dental clinical examination based on Decayed Missing and Filled Teeth (DMFT) index as outlined in the primary survey methods by the World Health Organization was also performed (47). The DMFT index determined the presence of dental caries and treatment needs. Patients were examined while sitting in the supine position on a portable dental chair using artificial light in the clinic. The Oral HIV/AIDS Research Alliance (OHARA) case definitions were used to record the oral mucosal conditions (48). The inter-examiner reliability was done by reexamining one tenth of the sample by each examiner, and the calculated kappa statistics was 0.81 for DMFT, and 0.87 for OHARA case definitions. After the clinical examination, the M-COHIP was administered.

Modified COHIP Administration

Best practices for scale development and validity determination should follow several steps, as explained in the 2018 paper by Boateng and co-authors (49). Generally, the steps include internal consistency and reliability determination; exploration of factors; confirmation of factors; and, the tests of construct validity through the discriminant and concurrent validity.

In the first phase of this PhD (Chapter 5), the qualitative exploration of the items in the COHIP tool resulted in more themes/items (46). Consequently, the broad OHRQoL domains consisted of (i) individual-level domain: oral health awareness, felt oral symptoms, impaired oral functioning and coping; (ii) external level domain: access to and negative experiences of using dental facilities; and (iii) social level domain: self-stigmatisation and social interaction. This resulted in a modified OHRQoL COHIP tool with 29-items and was used to measure OHRQoL among individuals in the two groups of adolescents in the current study.

The individual items or questions in the original COHIP questionnaire were 19 with five subscales viz: (Oral Health, Self-Image, School Performance, Socio-Emotional Wellbeing, Functional Wellbeing,). *Source of original COHIP Tool - With permission from Dr. Hillary L. Broder*(50). The new domains from the theme viz: Dental Access, Dental care Experience and Coping. The expert panel derived the items relating to the themes and based on the responses of the adolescents interviewed. Four items relating to 'Dental Access' questions, and three each for the 'Dental Care Experiences' and 'Coping' to a more extended 29-item tool .The modified tool was then piloted among adolescents in the clinic to ascertain the feasibility, comprehension and time-taken to administer it. The wording was changed for comprehensibility. This paper is about the validation of the tool after it was administered to two groups of adolescents.

The questionnaire was administered in form of an interview in English language .The following were the responses required from the participants: *never; almost never; sometimes; fairly often; all the time* had the event occurred in the past three months, attributed to one of the 29 items. The self-rated oral health expected from the question "how would you rate the health of your teeth/mouth in the past three months" responses ranged from *poor; fair; average; good and excellent*. All adolescents answered the questionnaire, which made the response rate to be maximum.

7.3 DATA ANALYSIS

Descriptive variables in the form of socio-demographic, Decayed scores, DMFT and M-COHIP scores were calculated. Bivariate analysis was done through the comparison of all scores, by dental caries prevalence (dichotomized as D=0 and D >0 and DMFT=0 and DMFT>0), by the research group, toothache as well as general oral health self-rating.

The modified COHIP score was calculated by adding the answer responses, which ranged from 1–145; with higher scores implying a poorer OHRQoL.

Cronbach's alpha was used to determine the internal consistency of the scale and the identified sub-scales (51). The α -scores of 0.5, 0.7, 0.8 and 0.9 means the sub-scale reliability is moderate, acceptable, good and excellent, respectively. It is recommended that for a sub-scale to have meaningful internal consistency, it should have at least three or more items or indicators (51). The average alpha score of 0.5 was kept as the items or variables informing them were three or more.

The construct validity was assessed by the measures of discriminant validity using ANOVA and Bonferroni post hoc test for differences of more than two means and independent t-test for differences between two means. The following hypothesis was assumed: participants with higher M- COHIP- score will have poorer self-rated oral health. Convergent and discriminant validity assessments were also performed based on modified COHIP scores and overall oral health self-rating, relatedness to toothache and active dental caries (D>0). Multiple logistic regression was performed to calculate the predictors of M- COHIP for dichotomous outcomes with odds ratios and 95% confidence intervals reported

The orthogonal rotated pattern matrix using factor loadings of 0.4 and above was conducted and resulted in five factors with COHIP 29 items and 502 participants. The Kaiser-Meyer-Olkin Measure showed sampling adequacy of KMO=0,870 while Bartlett's tests of sphericicity was χ^2 (406) = 2728.63, p<0.001 revealing that correlations between items were large enough for Exploratory factor analysis (EFA). The initial EFA done on all items explained 76% of the total variance and showed two factors with over one eigenvalues. The plot from the parallel analysis revealed six factors. However, we adopted a five factor loading based on similar studies (52) to determine latent factors to be retained and consistent with the original Broder tool (50). The multiple fit indices were used to determine the CFA model fit in order to verify the observed variables and factor structure. The Root Mean Square Error Of Approximation (RMSEA), Akaieke's Information Criterion (AIC), Bayesian Information Criterion (BIC),Tucker-Lewis Index(TLI), Comparative Fit Index(CFI) and finally the Standard Root Means Square Residual (SRMR). The values greater than 0.95 imply an excellent fit while 0.90 an acceptable fit. The SRMR acceptable fit should be less than 0.10 while the RMSEA value indicative of close fit is less than 0.05

7.4 RESULTS

Dental Caries Prevalence and Caries Experience

The overall mean decayed teeth for permanent dentition was 1.6 (SD=1.2), and the overall caries prevalence was a high 62.2 % among all adolescents. When disaggregated by group, the adolescents in the HIV clinic had lower caries prevalence of 53.7% than those in school at 66.2%, but higher mean decayed teeth (2.0 (SD=2.56) vs 1.2 (SD=1.26), p<0.001). The ALHIV selected from the wellness site displayed higher treatment component through the filled (F), and the extracted (M) teeth mean scores. These treatment scores (F and M components) were higher in the HIV group than in the school group. Those in the HIV Wellness group had at least one tooth restored/filled and extracted F=0.6 (SD1.1) and M= 0.7(SD0.8) due to caries than those in school whose averages were nil (F=0.2 (SD=0.4) and M= 0.3 (SD=0.8, p<0.001 (Table 7.1).

Similarly, in the Wellness group, oral mucosal lesions prevalence – denoted by OHARA>0 (at least one soft tissue lesion); was 21.7%. More participant characteristics can be found in Table 7.1 below.

Table 7.1: Socio-demographics characteristics and caries occurrence of the part	icipants
by the research group	

Trait	HIV wellness Site; n=226		School Site; n=	=278
Agemean(SD)	15.14 (2.10)		15.10(1.94)	Min to Max 11- 20yrs

	Frequency	Percentage	Frequency	Percentage
Age 11-15 years old	132	58.4	125	45.0
Age 16-20 years old	94	41.6	153	55.0
	226		278	
Male	103	47.0	195	70.7
Female	116	53.0	81	29.3
	219^		276^	
Self-Employed	34	19.3	105	40.4
Employed Parent	77	43.8	116	44.6
Unemployed Parent	65	36.9	39	15.0
	176^		260^	
Primary School	43	19.7	103	37.3
High School	175	80.3	173	62.7
	218^		276^	
Decayed=0	96	42.7	92	33.8*
Decayed>0	129	57.3	180	66.2*
	225^		272^	
OHARA=0	177	78.3		
OHARA>0	49	21.7		
	226	100		
D Mean(SD)	2.0(2.56)		1.2(1.26)***	
M Mean(SD)	0.6(1.09)		0.2(0.44)***	
F Mean(SD)	0.7(0.85)		0.3(0.89)***	
DMFT Mean(SD)	3.4(2.07)		1.6 (1.64)***	

***p≤0.001, *P≤0.05, ^ =missing values

Modified - Child Oral Health Impact Profile

The overall Cronbach's alpha was 0.88 for the 29-items. The five sub-scales in the Broder COHIP-SF tool were retained and, three new sub-scales added to calculate the reliability of the scale. All eight sub-scales had reliability ranging from 0.5 to 0.8. The overall M-COHIP score was 59.6 (SD=18.42), median 58 (IQR: 46 to 72). The lowest score was 14 and highest was 115. When reported by site, the HIV Wellness group score was 55.5 (SD=18.05), while that of the school was 63.6 (SD=17.42) (Table 7.2). There was a difference in the subscale scores between the two groups except with the 'dental access' and the 'dental care experience' subscale scores. Table 7.2

Sub-scales and Items	HIV wellness Site; n=226	School Site; n=278
	Mean (SD)	Mean (SD)
	Confidence Interval	
Total M-COHIP score	55.5(18.05)	63.6(17.42)**
	53.1-57.9	61.1-66.1
Oral Health Score	9.9(4.09)	11.3(3.91)**
	9.3-10.5	10.7-11.8
Self-Image Score	5.9(2.72)	6.5(2.44)*
	5.6-6.3	6.2-6.9
Social Emotional	11.7(5.09)	13.8(5.39)**
Wellbeing Score	10.9-12.4	12.9-14.5
School Performance	3.2(1.7)	3.6(1.9)*
Score	2.9-3.4	3.3-3.9
Functional Wellbeing	7.4(3.19)	8.8(3.34)**
Score	6.9-7.8	8.2-9.2
Dental Access Score	7.7(4.26)	7.6 (4.26)
	7.2-8.3	6.9-8.2
Dental care Experience	5.2(2.64)	5.6(2.72)
Score	4.9-5.6	5.2-5.95

Table 7.2: Mean M-COHIP scores and sub-scales score by research site

Coping Core	6.5(2.91)	7.2(3.26)*
	6.1-6.9	6.7-7.7

**p≤0.001, *P≤0.05

The factor analysis for the five hypothesised factors was done: see Table 7.3. Five components/factors were identified and included the new sub-scales termed 'Dental Access' and 'Coping' (Table 7.3).

Table 7.3: Rotated Pattern Matrix and unique variances of the five factor component
for the modified COHIP-29 in SA

	Components						
Ι	tems in the modified	Social-	Functional	Dental	Coping	Self-	Uniqueness
	COHIP Tool	Emotional	Wellbeing	Access		Image	-
		wellbeing	C			C	
1.	Had pain in your	0.232	0.413	0.073	0.312	-0.0559	0.6696
	teeth/toothache						
2.	Had crooked teeth or	0.226	0.308	0.080	0.208	0.127	0.7881
	spaces between your						
	teeth						
3.	Had discoloured teeth	0.414	0.100	0.234	0.053	0.108	0.7492
	or spots on your teeth						
4.	Had bad breath	0.415	0.152	0.094	0.277	-0.034	0.7183
5.	Had bleeding gums	0.169	0.356	0.010	0.354	-0.002	0.7193
6.	Been unhappy or sad	0.424	0.251	-0.020	0.297	0.184	0.6349
7.	Missed school for any	0.241	0.619	0.129	-0.042	-0.057	0.5375
	reason because of your						
	teeth						
8.	Been confident	-0.064	-0.001	-0.066	0.010	-0.561	0.6763
	because of your teeth						
	and mouth						
9.	Had difficulty eating	0.149	0.493	0.017	0.374	0.019	0.5947
	foods you would like						
	to eat						
10.	Felt worried or anxious	0.552	0.320	0.026	0.219	0.063	0.5404
11.	Not wanted to	0.469	0.214	0.170	0.087	0.175	0.6668
	speak/read out loud in						
10	class	0.500	0.100	0.1/0	0.000	0.114	0.5005
12.	Avoided smiling or	0.560	0.180	0.162	0.232	0.114	0.5605
12	laugning	0.0504	0.(2)	0.071	0.101	0.022	0.5050
13.	Had trouble sleeping	0.2584	0.030		0.121	-0.032	0.5078
14.	Ealt that you ware	0.4/4	0.141	0.089	0.050	0.040	0.7428
13.	ren mat you were	-0.008	0.029	-0.000	-0.050	-0.565	0.0521
16	Falt that you look	0.512	0.054	0.159	0.049	0 122	0.6003
10.	different	0.312	0.034	0.130	0.040	-0.132	0.0903
17	Had difficulty saving	0.401	0.231	0 117	0 132	0 165	0 7277
1/.	certain words	0.401	0.231	0.117	0.134	-0.105	0.1411
18	Had difficulty keeping	0.223	0 141	0 184	0 234	0.232	0 7882
10.	vour teeth clean	0.225	0.171	0.104	0.237	0.232	0.7002

19. Been worried about	0.567	0.028	0.225	0.142	0.103	0.5964
what other people						
think						
20. Had a problem with	0.180	0.044	0.690	0.247	0.058	0.4252
getting dental care						
because the						
clinic/hospital is far						
21. Had a problem with	0.232	0.090	0.608	0.307	0.015	0.4735
getting dental care						
because my						
parents/caregivers are						
22 Had a problem with	0.344	0.065	0.558	0.115	-0.024	0 5518
setting dental care	0.344	0.005	0.550	0.115	-0.024	0.3310
because my family						
cannot afford						
23. Had a problem with	0.182	0.149	0.563	0.090	0.126	0.6044
getting dental care						
because the clinics are						
closed						
24. At the dental clinic,	0.038	0.386	0.429	0.006	0.116	0.6516
they do not take my						
teeth and mouth						
complaints seriously	0.000	0.040		0.04 -	0.4.00	
25. At the dental clinic,	0.098	0.043	0.415	0.015	0.120	0.6228
they do not address						
my teeth and mouth						
complain: instead they						
focus on other issues						
26. Treatment of mouth	0.051	0.407	0.197	0.211	-0.010	0.7484
and teeth problems is	00001			0.211	00010	
too painful						
27. If I have a problem	0.107	0.081	0.090	0.362	0.054	0.8402
with my teeth or						
mouth, I do not tell						
anybody						
28. I do nothing when I	0.227	0.002	0.236	0.501	-0.017	0.6417
nave pain in my mouth	0.094	0.100	0.195	0.571	0.017	0.50((
29. I do not know what to	0.084	0.190	0.185	0.5/1	0.017	0.5900
	1	L			1	

The majority of items (10) loaded on the first component named 'Social-Emotional Wellbeing'. The second component had five items and constituted the 'Functional wellbeing' sub-scale as the items investigated the functioning capabilities of the participants concerning pain. Noticeably, the item/question 'Treatment of mouth and teeth problems is too painful' did not load with the 'dental access experience' but was clustered with this component on functional wellbeing (Table 7.3).

The third component was logically related to the six items investigating dental facility use and access and thus, 'Dental Access'. The fourth component composed of two items investigating participants coping or handling of the oral and teeth problems and, was thus, named 'Coping'. The third item related to coping did not load at 0.4 loading cut off points. However, Coping subscale was an important theme arising from the initial questionnaire development based on the qualitative interviews. It was retained because the third item, using the cut-off point of >.32, it can be added than deleted to render a construct to have three items, as suggested by Worthington and Whittaker (2006)(53) and Carpenter (2017)(54). Theoretically, the deletion and addition of item is an iterative process that should logically be guided by the theoretical convergence.

The fifth component was composed of the two items originally in the Broder COHIP termed 'Self-image' and were retained as being only two in their sub-scale with negative factor loadings. The subscale 'Self-Image' has two items from the original questionnaire and was retained because it is the only positive phrased subscale; even in the original, it only had the two items. Also, two-itemed factors or constructs are allowable if the items are highly correlated (i.e. r < 0.70 (53). The 'self-image' subscale interitem correlation coefficient was 0.392.

Four items did not load anywhere with the cut off points of <.4 (Table 7.2). These are: a) Had crooked teeth or spaces between your teeth; b) Had bleeding gums; c) Had difficulty keeping your teeth clean and lastly; d) If I have a problem with my teeth or mouth, I do not tell anybody.

The Broder COHIP-SF tool had the following five dimensions: oral health, functional wellbeing, socio-emotional wellbeing, school performance and self-image. Three of the five sub-scales identified in this modified COHIP tool were found in the Broder COHIP-SF tool (45).

Table 7.4 displays the Cronbach's alpha coefficients for all sub-scales ranging from 0.50 to 0.81. 'School Performance' had the lowest scale reliability coefficient of 0.50 (Table 7.4).

Table 7.4: The tool reliability analysis of the old and new sub-scales [changed to2decimals]

ItemsIn the past three months have you	Item-test	Item-rest	Alpha if
	correlati	correlatio	item
	on	п	deleted
Oral health sub-scale (Alpha = 0.59)			
1. Had pain in your teeth/toothache	0.65	0.38	0.47
2. Had bleeding gums	0.62	0.35	0.50
3. Had crooked teeth or spaces between your	0.59	0.30	0.52
teeth			
4. Had discoloured teeth or spots on your teeth	0.58	0.29	0.52
5. Had bad breath	0.58	0.28	0.52
Self - Image sub-scale (Alpha = 0.56)			
6. Felt that you were attractive			
7. Been confident because of your teeth and			
mouth			
Social and emotional wellbeing Sub-scale (Alpha			
= 0.78)			
8. Been teased, bullied	0.64	0.45	0.75
9. Been worried about what other people think	0.72	0.56	0.73
10. Been unhappy or sad	0.68	0.50	0.74
11. Avoided smiling or laughing	0.71	0.54	0.73
12. Felt that you look different	0.63	0.44	0.75
13. Felt worried or anxious	0.74	0.59	0.72
School performance sub-scale (Alpha = 0.50)			
14. Missed school for any reason because of your			
teeth			
15. Not wanted to speak/read out loud in class			
Functional wellbeing sub-scale (Alpha = 0.56)			
16. Had difficulty eating foods you would like to	0.72	0.42	0.41
eat			
17. Had trouble sleeping	0.71	0.41	0.41
18. Had difficulty saying certain words	0.61	0.26	0.55
19. Had difficulty keeping your teeth clean	0.61	0.27	0.54
Dental access sub-scale (Alpha = 0.81)			
20.Had a problem with getting dental care because	0.85	0.72	0.73
the clinic/hospital is far			
21.Had a problem with getting dental care because	0.80	0.62	0.77
my parents/caregivers are usually at work			
22.Had a problem with getting dental care	0.82	0.67	0.75
because my family cannot afford			

23.Had a problem with getting dental care	0.74	0.53	0.81
because the clinics are closed			
Experience with dental care sub-scale (Alpha =			
0.66)			
24.At the dental clinic, they do not take my teeth	0.80	0.53	0.50
and mouth complaints seriously			
25.At the dental clinic, they do not address my	0.83	0.56	0.45
teeth and mouth problems when I complain;			
instead they focus on other issues			
26.Treatment of mouth and teeth problems is too	0.71	0.356	0.72
painful			
Coping sub-scale (Alpha = 0.60)			
27.If I have a problem with my teeth or mouth, I	0.71	0.33	0.59
do not tell anybody			
28.I do nothing when I have pain in my mouth	0.77	0.43	0.44
29.I do not know what to do when I have pain	0.76	0.43	0.45
Overall Cronbach-Alpha (for 29 items)		0.88	

The item-rest correlations were 0.79 to 0.85 for all items. The item-rest correlation indicated the correlation between an item and the whole scale as formed by all items. The Alpha if item deleted showed that sub-scale reliability becomes poor when the item is deleted save for the item 26 "Treatment of mouth and teeth problems is too painful" under the construct Experiences with dental care.

Construct Validity: Convergent and Discriminant Validity

Table 7.5 displays the different M-COHIP scores with several variables to test the discriminant and convergent validity hypothesis. The higher scores imply a poorer oral-health-related quality of life. The mean M-COHIP scores decreased with the better oral health self-rating and increased with self-report of toothache, active decay and caries experience (p<0.001). The M-COHIP/OHRQoL scores for participants recruited from the school sites were higher than those at the HIV Wellness site. The sex of the participants did not influence the M-COHIP score.

Table 7.5: Comparison of Modified- COHIP by different variables for discriminant andconvergent validity

Variable	Sample	COHIP-MODIFIED SCORE	p-value
Oral health-self rating	Ν		
Poor	66	67.55(20.51)	***p≤0.001,
Average	119	63.7(16.94)	
Good	207	54.84	
Total	392		
Toothache			
Rarely	242	51.88(15.36)	***p≤0.001
Sometime	181	64.80(16.84)	
Always	70	74.44(18.87)	
Total	493		
Active decay			
Decayed=0	188	57.29(1.31)	*P≤0.05
Decayed>0	309	61.06(1.06)	
Total	497		
Caries Experience			
DMFT=0	160	57.03(1.47)	*P≤0.05
DMFT>0	344	60.78(0.98)	
Total	504		
Sex			
Male	298	60.46(1.03)	>0.05
Female	197	58.45(1.38)	
Total	495		
Site			
HIV wellness	226	55.54(1.20)	***p<0.001,
School	278	63.59(1.08)	
Total	504		

***p<0.001, **P<0.01, *P<0.05

 Table 7.6: Multivariate Linear Regression analysis for factors that may influence

 OHRQoL (Modified-COHIP) among all participants

Exposure Variable	N (%)	Regression	95% Confidence Interval	
		coefficient	Lower	Upper
Age –Mean (SD)	15(2.0)	-0.4	-1.1	0.3
Male	298(60.2)	1		
Female	197(39.8)	-0.9	-4.1	2.4
Dental caries =0	160(31.8)	1		
Dental caries >0	344(68.3)	4.5**	1.4	7.5
HIV Wellness	226(44.8)	1		
School	278(55.2)	3.3*	-0.0	6.6
Toothache -Rarely	242(49.1)	1		
Sometimes	181(36.7)	10.6***	7.3	13.9
Always	70(14.2)	22.4***	17.9	26.9
Poor OH self-rating	66(116.8)	1		
Average OH self-rating	119(30.34)	-1.16	-5.8	3.4
Good OH self-rating	207(52.8)	-8.3***	-12.6	-4.1

***p<0.001; **p<0.01*p<0.05

Discriminant validity on groups was expected to demonstrate higher scores with a higher caries prevalence and with toothache reports. As depicted in Table 7.6, when adjusted for potential confounders such as age, sex, group, oral health-self-rating and toothache, the caries prevalence and toothache were significant predictors of M-COHIP scores. The participants recruited from the school sites had a higher caries prevalence when compared to those in the wellness site, and the p-value was significant (p<.05). Age and sex were not significantly associated with modified COHIP scores in Johannesburg.

Confirmatory Factor Analysis

Based on the theoretical model, the relationships between the three latent factors viz. individual, external level factors and social impact level factors were explored using the confirmatory factor analysis model from structural equation modelling framework. The

modelling was done with the observed eight factors (Fig 7.1). The social impact latent factor was not included as it had only one sub-scale associated with it (socio-emotional wellbeing).

The CFA overall fit statistics for the model are χ^2 test (p < 0.00), RMSEA= 0.05 with corresponding 90% confidence interval of 0.04-0.07, SRMR = 0.034, TLI = 0.959, CFI = 0.972. The overall fit indices generally indicated a good model.

The social impact latent factor was added to the individual latent factor and was highly correlated to this latent factor. Social image sub-scale poorly correlated with individual-level factor. There was a high correlation between the individual and the external latent factors displayed by the high covariance. The relatedness between the latent factors is also theoretically explained by the conceptual framework of OHRQoL which explains that, the two latent factors or dimensions together have an impact on the oral health related quality of life.

The final model had two latent factors viz. individual and external levels factors related to one another (Fig 7.1).



Figure 7.1: Confirmatory analysis Model showing relationship between latent, observable factors and number of indicators/sub-scales relevant in the study setting

According to Kline (55), the standardised loadings (r2) should be at least 0.70 to display good convergent validity. The acceptable cut off points are from 0.5. The dental care access (0.67) and the dental care experiences (0.62) showed good convergence to the external level latent factor. Likewise, the oral health, functional wellbeing and the socio-emotional wellbeing had the highest convergence ($r_2 > 0.70$) to the individual latent factor.

The school performance and coping sub-scale, were marginally correlated with the loading of 0.55 and 0.52, respectively. The eighth, Self- Image sub-scale had the weakest convergence with loading less than 0.5 (0.44)

7.5 DISCUSSION

The 29-item Johannesburg, South African version exhibited acceptable reliability and validity. The two sub-scales (Self-Image and School Performance) in this M-COHIP and the original tool by Broder and colleagues, had the least but acceptable alpha scores even though they only had two items each. The M-COHIP is the result of the contextual findings of a prior qualitative inquiry, which suggested the addition of three more sub-scales to capture the relevant factors important in the setting (46). These new sub-scales 'Dental care access', 'Experience with dental care', and 'Coping' were added, and the final tool displayed very good reliability and validity.

The scale reliability using Cronbach's alpha revealed an acceptable level of internal consistency and reliability ranging from moderate (0.5) to high alpha scores (0.8) for all eight sub-scales and was excellent for all the 29 items at 0.88. Albeit the additional sub-scales in our version, its overall score is similar to the one in the Ahn et al. study in their Korean sample of 0.88 (56), El Osta et al. found 0.88 in their Caledonian sample (57) and Li et al. with their 0.88 in a Chinese sample. Elsewhere, Broder found a comparable 0.91 in the Canadian children participants (45). All the previously mentioned studies used the original 34-item COHIP tool. The developers of Broder et al. also shortened the original 34-item tool to the Shortened Form-COHIP (45), where Agnew et al. in Australia (58) and Arheniam et al. in Libya adapted and used it. The latter authors found the Cronbach-alpha of 0.9 and 0. 84, respectively (52, 58).

Our study found the M-COHIP score of mean 59.6 (18.42) and median score of 58 (IQR: 46 to 72). When reported by site, the HIV Wellness group score was 55.5 (SD=1.2), while that for the participants recruited from the school sites was 62.9 (SD=1.09). The modified tool displayed the capability to score the adolescent oral-health-related quality of life. In their application of the shortened forms of the tool, Arheiam and colleagues scored their participants 61.1 using COHP-SF, while a Chinese study reported 62.2. Self-image as a sub-scale performed well with highest correlates compared to the current study where it had an average Cronbach-alpha score of 0.6. However, School performance had the lowest alpha of 0.5 (52). The two items measuring self-image in our study, and the original Broder study were the only positively worded phrases out of negatively worded statements. For the current study, the items were reversed similar to the Caledonian study when calculating scores; their overall COHIP-SF scores were 109 using the full 34-item COHIP tool (39).

When it comes to the Self-Image dimension - regardless of the correlation, the reliability was high (0.6) enough for the sub-scale to be retained as posited by Worthington and Whittaker in the theory of scale development (53).

Poor oral health self-rating inversely correlated with higher modified COHIP scores confirming the ability of the scale to differentiate the behavioural manifestations. Further, less decay, mild toothache and access to care for diseases may have contributed to the overall better mean scores between two groups of adolescents in the two research groups. Caries prevalence was generally high (62%) among this cohort of adolescents combined. However, adolescents living with HIV were receiving care from the wellness centre in the form of treatment and prevention of diseases. The results showed a lesser caries prevalence and a slightly more treatment component care seen by extraction services (M) and the teeth restored (F) compared to the participants recruited from the school sites. The modified – COHIP tool, when applied to this setting, among these participants, could differentiate the OHRQoL scores in the two groups. The pain symptom was congruent with the dental caries status.

The adolescents in the school site reported higher modified COHIP (62.88) than the participants recruited from the wellness site (55.54). The exploratory factor analysis (EFA) led to five tentative dimensions compared to the four dimensions in Arheniam et al. study(52). Worthington and Whittaker suggest that during scale development or adaptation; the most rational and logical approach is to conduct EFA after confirmation by confirmatory factor analysis (CFA)(53). Subjective and objective thinking is thus applied at this stage following EFA. This led to three new sub-scales added to the original five and to constitute the 8-sub-scale M-COHIP. This process was echoed by Arheniam et al. in their Arabian version where initial EFA identified a four factors solution even though the original had three factors (52). The EFA is a fluid and dynamic elimination and revision stage that is used to cluster items (53). The factor analysis and the confirmation echoed the tools' consistency in the sample and this setting.

The M-COHIP tool, as applied to the setting, was found to have good discriminant and convergent validity. For discriminant validity, comparison with the predetermined hypotheses was confirmed. The analysis indicated that the tool distinguished those with reported toothache, and diagnosed with dental caries to be different by scoring higher impacts depicted by high M-

COHIP scores. This is in the same tone with what Arheniam and co-authors' results showed that active decay had poorer OHRQoL (52).

In addition, the latter authors showed that those with dental treatment needs and those unsatisfied with their dental health also had poorer OHRQoL. Our study showed that those with a higher decay component were mostly in schools, hence, being selected from the school was a predictor to having a poorer oral-health-related quality of life.

Convergent validity was correlated with oral health self-rating. The impacts decreased with lower scores, implying a good OHRQoL score and good global rating. The latter was also reported by several studies where poorer self-rated oral health interconnected with poorer impact score and poor OHRQoL (56, 57, 59). In addition, convergent validity is usually appraised by the correlation matrix (60). The relatedness detected the evidence of the validity of the estimated item through correlations of the overall modified COHIP score, and the subscale with the perceived self-rating by participants. The results are comparable to Agnew et al., 2017, where the same proxy elements for the positive global rating was related to their COHIP Scores (58).

Confirmatory factor analysis was used to validate the relationships following the EFA. The relationships were also based on the priori theory of the relationship between individual and external factors influencing the quality of life. Eventually a five factor structure was adopted using the Kaiser criterion and the parallel analysis.. The use of EFA as an item or factors selection process may yield various outomes when the items are both formative and reflective. The number of factors may range from two to nine(53)

The eight sub-scale in the modified COHIP tool were subjected to structural equation modelling to explain the associations between the latent and observed variables based on the priori theory. Items were added to the modified COHIP to include those that were not represented in the original COHIP based on contextual qualitative exploration. The outcome of the CFA for the data yielded a model fit for two latent variables, namely Individual and the External level factors. The former ended up with five subscales, each with several items/questions. The latter had two sub-scales confirming the theory. The CFA exercise proved effective, as it confirmed the validity of five observed sub-scales related to the individual latent variable and the two observed sub-scales related to the external level latent variable for the modified COHIP tool in the setting.

The overall scale demonstrated that for the adolescents in the school group, toothache and caries prevalence were predictors of M-COHIP Scores. The more the toothache and caries prevalence for those in schools, the higher the M-COHIP scores and impacts. The variables such as age and sex did not yield any differences in impacts.

This is unlike the Broder study, where the younger children had poorer OHRQoL than older children. The lack of sensitivity to age in our study may be related to homogenous age-phase by all adolescents, unlike the prior study where they had pre-adolescents from eight years with primary dentition. In addition, the older adolescent tends to cope better. Interestingly, in the Agnew et al. cohort, the older adolescent children displayed differences in the social and emotional dimension. The results were attributed to the expressiveness nature of this somewhat volatile life phase. Perhaps follow up longitudinal study designs to explore other differences between groups are necessary for our setting.

This study is not without limitations; the self-report nature of OHRQoL is subjective and depends on the recall ability of the participants. The participants were, however, required to report on their recollection from the day of the examination to three months prior in an attempt to overcome recall biases. Scholars deem reliability and validity as incremental and unending processes. Thus, the reported psychometric properties of our M-COHIP instrument are acceptable for this setting and participants under the described circumstances. Test-retest assessment, which is an adjunct to measures of reliability, was not possible in the setting due to the structure of the HIV centre participant burden. However, the robust validity measures employed showed good results.

CONCLUSION

The summary key findings are that Modified-COHIP displayed good psychometric properties. Further, OHRQoL, regardless of HIV status, was impacted by the dental caries status. This finding support the notion that with regards dental caries, the predisposing factors are largely similar regardless of the HIV-infection. Our study showed that those with higher decay component were mostly in schools, hence, being selected from the school was a predictor to having a poorer oral health related quality of life, this is opposed to being selected from HIV Wellness site. This comparative study found that being on treatment at the HIV Wellness site, might be protective against oral diseases. The ALHIV group had a comparatively lower impacts than those in the school group due to less toothache and dental decay. The overall adolescents' OHRQoL scores were related to the high untreated caries, toothache reports, a poor self-rated oral health and being in schools. The exploratory factor analysis and the confirmation analysis echoed the tools relative consistency in the sample and in this setting. Therefore more studies suggested to retest the new contextual subscales such as "Coping". The school performance and self-image, present the in the original tool, had poor factor loadings.

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CHAPTER 8: DISCUSSION AND RECOMMENDATIONS

8.1 INTRODUCTION

This final chapter of the thesis incorporates and discusses the essential findings of this PhD study and concludes with recommendations on policy and programmatic implications for a comprehensive adolescent oral health service package.

This chapter is cognizant of the robust discussion sections of the respective objectives and chapters of the thesis already presented in Chapters 4 to 7. Consequently, Section 8.2 summarises, discusses and attempts to integrate the key findings of the respective objectives and chapters. In Section 8.3, a commentary is provided on the conclusions with scholarly contributions from this PhD. Section 8.4 highlights the recommendations from the study and provides suggestions of a way forward and post-doctoral research actions.

This mixed-methods study has helped to generate useful knowledge on the oral disease burden, specifically, dental caries and the oral mucosal lesions found among adolescents living with HIV and on antiretroviral treatment. The study has brought to attention the perceptions and experiences of adolescents living with HIV on their oral health concerns, challenges and oral-health-related quality of life impacts and psychosocial issues. More importantly, this study has introduced a context and participants' specific measurement tool adapted for South African adolescents and for the first time through content refinement and additions. The results are discussed in the context of all the PhD study's objectives and results.

8.2 SUMMARY KEY FINDINGS AND DISCUSSION

In order to present a continuous narrative description, I have opted to write in the logical process, and the study objectives are interlocked. The discussion ends with the systematic review paper, which will present a modified conceptual framework based on this PhD, which includes African studies' review findings. The objectives will still be highlighted for the reader.

The perceptions and experiences of adolescents in Johannesburg with oral conditions and OHRQoL

The key messages to be discussed from this objective are that the health-seeking behaviour, coping, social support and oral health perceptions and experiences impacted adolescents' perceptions of OHRQoL. The population of ALHIV experienced broad and interrelated issues; living with the infection impacted on their lives and sometimes manifested as self-isolation. The ALHIV also seemed to have learned to be accustomed to some symptoms and may have internalised pain and infirmities. The adolescents placed a higher value on some of the themes, such as coping and social or family support.

The findings from this phase of the study showed that the adolescents' perceptions and experiences were interconnected and influenced the adolescent practices and health-seeking behaviour. The service delivery gaps and complaints with services acquired were significant, on their own and may impact on health-seeking practices and OHRQoL. For instance, health facility utilisation and health-seeking behaviour were hindered by dental care access complaints at various dental clinics, and these impacts on their oral health status and OHRQoL. ALHIV and the undiagnosed group of adolescents equally expressed this concern. In contrast, a hindrance to dental visits among ALHIV in Brazil was attributed to the sense of coherence -SOC (the enduring dynamic feeling of confidence) (61). Further, adolescents in Brazil with lower SOC were more likely to visit dental care sites for check-ups compared to those with higher SOC who were less likely to visit dental care providers (61). The authors attribute the latter to the study participants' age. Adolescents' oral health behaviours are still likely to be influenced by parents instead of SOC, unlike in adults where the confidence in self and SOC is high. In addition, adolescents with high SOC were more likely to frequently brush teeth and practice optimal oral hygiene hence less dental visits. On the other hand, Baker and Mat findings in their study to assess the factors affecting young people's daily activities noted that the SOC was related to the lesser OHRQoL (26).

In an American study by Coulter and colleagues, they found that adults living with HIV did not use dental care regularly unless they went to an HIV wellness clinic (62). This pattern is similar to our observation in this study among adolescents. In other words, the use of dental care was linked to the availability of dental care at the HIV wellness clinic. A 'one-stop-shop' facilitated access to dental services, and those who did not get dental care from the HIV wellness clinic did not receive dental services anywhere (62). This observation may explain the higher oral disease burden and care needs found among adolescents in the school group who did not receive routine oral health services as those who seek care at the HIV Wellness Centre.

This study found that self-isolation and stigma may have impeded early care-seeking and has the potential to exacerbate preventable oral conditions. This finding was echoed by Lambert and co-authors in their Cape Town study of PLHIV, which highlighted the importance of not delaying care as it may worsen the oral problems (63). However, stigma may not always be from patients but the health care providers, as reported by Jessani et al. (64). They added that discriminatory behaviour by providers of health has the potential to deter health-seeking and perpetuate the unmet oral health needs (64). This gives more impetuous to the notion that wellness clinics should also provide dental care since the patient (ALHIV) and the staff are familiar with the underlying conditions of the patient (HIV).

Coping and enduring ill-health or ignorance of oral conditions has the potential to lead to delayed care until the oral signs and symptoms become worse. The ALHIV in our study demonstrated a tendency to cope with or endure pain and illness, possibly due to their history and experience of living with HIV and sometimes AIDS. Similarly, a Canadian study among PLHIV found that those who had been living with the disease for five or more years were able to learn, adapt and cope with the stress caused by the initial HIV diagnosis (64).

Negative oral-health-related quality of life scores were consistently associated with either pain symptoms, self-rated pain reports and or poorly self-rated oral health. Chaffee at et al. in Brazil noted that dental caries pain symptoms were related to negative child family experiences (65). Ironically, families with lower socio-economic lifestyles reported lesser impacts. The authors argue that local contexts may alter perceptions, especially for those with low socioeconomic status. Different markers of effects based on individual or prevailing group contexts may explain this finding. On the other hand, Baker and co-author report greater functional impacts from having symptoms associated with the poorer perception of health and thus a worse off quality of life (26).

In later chapters of this PhD, the ALHIV had relatively better OHRQoL than those in the school group. Besides the coping explanation, the cognitive dissonance theory may explain the discordance between perception and experience, including the struggle between competing

health needs versus oral health needs. Chaffee et al. argue inconsistent findings in their study may be because of the cognitive dissonance between the perceived experiences and the experience; in their case, it was the parent of HIC, who despite high caries experienced, reported lesser impacts (65). Discordance and the competing health interests have the potential to minimise the impacts of oral conditions; that may be worrisome, especially for the ALHIV who live with oral lesions.

Lastly, the positive family or social support theme from the qualitative exploration is applauded as it implies adolescents' ability to seek care. Khatri and colleagues support the idea that the family environment is a critical enabler to improving oral health as well as OHRQoL young individuals (66).

The important thing to appreciate about family support is that it enhances health-seeking activities to relieve oral diseases and symptoms. This is more so important as, in the subsequent objective of this PhD, evidence shows how, one in five of the ALHIV still require oral mucosal care, and every second ALHIV have unmet oral health needs. Interlinked to that is the emerging element of implied resilience and endurance of symptoms which may be positive as long as it does not delay oral health care.

The emerging themes from this paper such as coping, self-isolation, oral signs and symptoms, family/social support and strong opinions on dental care and use are noted and could strengthen current interventions and inform the future strategies. For instance, the findings can be used to advocate for and improve the provision of comprehensive and multidisciplinary HIV treatment and support with greater integration of oral health services for adolescents living with HIV. The adolescents' position on the various themes such as stigma and self-perception, symptom endurance and experience of using health services is similarly relevant in the context of universal and routine HIV treatment in South Africa.

Equally important is the need to re-interrogate the extent and implication of stigma (internal and external) among ALHIV given current advancements in HIV care and broader access to treatment.

Epidemiological updates on oral conditions among ALHIV on antiretroviral treatment

The burden of disease in the new emergent group of ALHIV was assessed to identify any emerging patterns and burden of oral diseases relative to what has been previously reported. In this regard, the findings of this PhD are summarised in Table 8.1

Table 8.1: Epidemiological updates on oral conditions among ALHIV on antiretroviral treatment

- Linear gingival erythema was observed in one out of every five ALHIV but this study also found out that oral mucosa lesion (OML) such as necrotising ulcerative gingivitis was rare.
- There was significant presence of dental caries and it was associated with immunological status of the adolescents.
- Dental caries contributed to the prevalence of OML.
- Positive oral health practices provided a protective effect , conversely frequent consumption of sugary diet and poor oral hygiene habits contributed to dental caries occurrence.
- Study also highlights the protective effect of HIV treatment on the decreasing but present burden of oral conditions.

Our study is one of the first to provide the epidemiological update on the patterns of the oral mucosa conditions in a population of South African ALHIV on ART (67). Despite the population being on the combination of antiretroviral treatment and frequent use of health services, there is a pocket of oral conditions and unmet needs in the target group.

With regard to gingival /mucosal conditions, similar patterns were reported by Liberali et al. in their study of reviewing oral conditions of participants in Australia after ten years of HIV management. The authors reported that PLHIV, including adolescents, still had significant oral health needs mainly related to the infection of the periodontium (68). The authors raise the need for ongoing monitoring of the cohort, more so, that periodontal infection (of which linear gingival erythema is one such infection), should not be underestimated as these gingival infections are common in chronic diseases compared to the general population.

Albeit reported side effects, the benefits of being on lifelong use of ART are lauded as the life expectancy of the ALHIV and PLHIV has remarkably increased. Xerostomia and hypermelanotic pigmentation due to ART has been observed elsewhere (69) but not in this study. Other oral mucosal conditions such as oral warts were extremely low in our study; there were only two cases among 407 enrolees. Our results are similar to the studies in South-Eastern Asia such as in a Thailand study (69) where no oral warts were reported; in a systematic review, Arrive et al. reports a similar trend in African cohorts (42). However, there are reports of an increased occurrence of oral warts in the Western cohorts with the use of highly active antiretroviral treatment (70-72).

Oral mucosal lesions type has changed from what was usually reported in the early times of HIV infections (42). Oral soft tissue lesions were, in the early times of the HIV epidemic, used in poor resource settings as a screening tool for possible HIV infection. Even in this stage of the HIV epidemic with advances in the treatment regimen, oral soft tissue lesions remain a signpost and early signal for poor treatment adherence. A significant improvement in the oral mucosal lesions appearance/prevalence observed in our study may imply a good treatment adherence among our study participants.

With reference to dental caries, several pieces of literature have reported the effect of HIV infection as associated with cariogenesis (32, 73, 74). The initial study phase of the PhD project reported a high caries burden among ALHIV when no comparison group was examined. In addition, Liberali et al. and Lin et al. went on to report on the occurrence of hyposalivation and the related xerostomia in chronic use of the protease inhibitors antiretroviral treatment which causes enlarged salivary glands (68, 75). Xerostomia is a predisposing factor for cariogenesis as it creates an environment where there is minimal protective saliva with immunoglobulins to ward off S. Mutans, the etiological bacteria. More interestingly, Nittayananta et al. raise a not commonly reported effect that HIV-long term infection might also decrease saliva irrespective of combination ART use (69). Nittayananta et al. report that salivary flow rates of PLHIV on the longer duration on combination ART were considerably lower than in those not on combination ART (68, 69). This decreased saliva rate, which would also apply to our study cohort, would explain the higher caries prevalence among HIV infected patients. However, these findings remain controversial as reports by Navazesh and co-authors' suggestion that raised HIV RNA levels are associated with xerostomia and not necessarily ART use (76). Therefore, this field needs more specific clinical studies.

The next phases of the PhD project underscore the advantage of comparator groups in attributing the pattern of oral disease burden to HIV infection. The HIV infection may be directly related through the salivary gland-related onslaught that results in xerostomia (69, 76, 77). The HIV infection also is a predisposing factor among other predisposing factors such as behavioural (oral hygiene and dietary), socioeconomic (access to preventive dentifrices and facilities) to dental caries. The current study reports an association of poor oral hygiene and high cariogenic diet with dental decay. We further found high levels of dental caries, especially among those with poorer immune states evidenced by higher HIV viral loads that may have reduced immune response to streptococcus mutans onslaught.

In our comprehensive study with a comparison group, predisposing and enabling factors show similar occurrence of dental caries in our undiagnosed group of participants and HIV infected participants with low viral loads. The sugary diet from the ALHIV self-reports and the possible use of fortified meals seen commonly in immune-compromised status, may inadvertently contribute to the oral disease. Similar results have been reported in the USA between a cohort of HIV infected youth and the general population (35) and in a recent Ugandan study (78). In our study, it was encouraging to note that those with positive oral health behaviour traits experienced lesser dental caries occurrence.

The findings have implications on the necessity to promote treatment adherence and positive oral health behaviour among ALHIV in South Africa. Dental caries results in pain that might affect the tooth brushing and flossing habits. So minimal or no removal of plaque and the oral microorganisms will increase gingival inflammation and linear gingival erythema. That is why dental caries contributed to the oral mucosal lesions. The current findings have implications for the financial costs of dental treatment and the opportunity costs for both young patients and their parents for time off work and school.

The naturally high oral disease will lead to participants showing disease signs with symptoms impacting on their daily activities; affect the psychological/emotional/ social status; thus, quality of life. In our study, a high prevalence of dental caries was reported to be associated with the presence of oral mucosal lesions and in turn, led to the oral-health-related quality of life impacts. These impacts are deliberated at length in the next section.

8.2.3 Validation of the modified Child Oral Health Impact Profile (COHIP) among Adolescents in Johannesburg, South Africa

Oral related quality of life impact was assessed by using a new contextually modified tool. It was necessary to validate and ascertain the robustness of the modified tool before it can be recommended and used widely (1). The initial postulate in the study was that: adolescents in South Africa may have thoughts, views and perceptions of OHRQoL that are different from adolescents in settings where the existing OHRQoL tools were developed. Traebert and colleagues support this position, where they report that different populations may behave differently to measurement tools based on their ethnicity and culturisation (79). Koot and Wallander went on to report that the youth, specifically adolescents, as a phase in life, have the propensity to behave and view things in their way dissimilar to the rest of the population (80).

Some key findings of this objective include that the Modified-COHIP displayed good psychometric properties. Further, OHRQoL, regardless of HIV status, was impacted by the dental caries status. This finding supports the notion that with regard to dental caries, the predisposing factors are mostly similar regardless of the HIV infection. The findings are similar to a study by Birungi et al., where for the primary dentition, untreated caries and quality of life impacts were high in both HIV-exposed and unexposed children (78).

It was interesting to know, however, that those in this study's school group (of undiagnosed adolescents), the impacts scores were higher. The explanation may lie in the dental caries severity and related pain symptoms. The analysis by toothache report revealed that the presence of symptoms was directly related to the OHRQoL impacts. We also found that adolescents' perception of oral health rating proved to be congruent with their poor impacts.

Lastly, the modified tool was still within the explanatory confines of the oral-health-related framework. However, the study unpacked more variables within the individual-level factors which are deliberated on in the next section of the systematic review and the conceptual framework.

Initial literature nearly five years ago -2015- in the field of oral-health-related quality of life and children (including adolescents) living with HIV infection revealed five studies, four were in Brazil(33, 37-39), and only one was conducted in Africa, Kenya(28). All of the participants in the mentioned studies were on ART, either 60% to 100%. However, all studies did not use

comparator groups, they reported a high prevalence of oral diseases and also poorer oral-healthrelated quality of life impacts on the participants due to the oral conditions. Unlike most previous studies, our study found that being on HIV treatment might be protective against oral diseases with our ALHIV group with suppressed viral loads as a result of treatment. This rendered them having comparatively lower impacts than those in the school group.

When looking at the adults' cohorts, a comparative study of both groups by Mulligan and coauthors report an average of 10% poorer OHRQOL of HIV-infected women than HIVuninfected women. The authors explain the difference may be due to other significant behavioural and clinical oral health factors such as periodontal diseases, smoking and drug use. Nonetheless, the study noted that HIV infection was also responsible (81).

The reasons for oral disease impacts may also lie in the HIV status or immune status. A South African study among adults with HIV infection and not on ART about a decade ago depicted poor impacts due to the oral conditions (82). Thus, the effect of ART adherence is remarkable.

Noting the multiplicity of factors that influences oral conditions and OHRQoL, it is essential to revisit the conceptual framework for clarity on their interconnection. The next section of this chapter presents the individual and environmental determinants OHRQoL reported in this study against findings from similar studies across Africa.

8.2.4 A review of factors contributing to the oral-health-related quality of life due to the oral conditions among adolescents

The Sischo and Broder (5) framework postulates that individual and environmental dynamics collectively and simultaneously influence the adolescents' functional status and physical symptoms and has a bearing on how they perceive their oral health and their oral health quality of life (5). This position is reinforced by the studies that have confirmed that OHRQoL is dependent on the context, socialisation and the environment (4, 6, 80). My PhD study conducted the first systematic review to identify the proximal and distal factors contributing to the OHRQoL in the African children context to interrogate the application of the OHRQoL framework.

The findings from the systematic review suggested that in the African setting, oral health perceptions were not a contributing factor to OHRQoL. Instead, the pathway to OHRQoL in Africa was directly from symptoms and socioeconomic status. For example, socioeconomic

status (when private versus public school attendance proxy), gum problems and children consciousness/psyche came out as the predictors at both individual and environmental levels from the East African and West African studies, strikingly; after rigours meta-analysis, dental caries was not an influencing factor.

Instead, additional determinants of OHRQoL such as satisfaction with oral health, dental access, and oral health behaviour came out strongly from my PhD research study conducted in South African.

This observation may suggest the determinants of OHRQoL in Johannesburg, South Africa resemble what is reported in high-income countries and atypical of the observations across Africa. For instance, perceptions or satisfaction with oral health and association with OHRQoL came out firmly from the children and or adolescents or caregivers' reports in countries such as Canada (8, 83), Saudi cohort (11, 84), Brazil (12) and UK (85) participants. Patrick et al. attribute this difference to the embedded cultural influence (86). South Africa is, however, among the few African countries classified as an upper-middle-income economy. Further, South Africa is also a highly unequal society often aptly described as "a nation of two economies". As such, that which is applicable in its economically vibrant Johannesburg may not be tenable in other parts of the country (19).

With regard to issues of access to dental care, the dental facility utilisation, and complaints arising from the SA context, it shows the agency that the adolescents possess. Comparing this finding with the Ugandan participants in my systematic review, it ought to be noted that dental access did not influence the oral impacts (87).

Findings from a majority of the studies suggest that the children from families with higher parental education and family income had better OHRQoL; family structure, household crowding and presence of siblings were significant predictors of children's OHRQoL (88-90). This matter was also confirmed in a study of 12-year-old Thai children where children of low socioeconomic status were more likely to have a high level of dental caries and concomitant OHRQoL impact (91). From my South African study (as reported in Chapter 5), parents' employment status was related to the dental caries high prevalence. It was such that children with working parents reported a higher prevalence of dental caries that may suggest childcare challenges among working parents in inner city Johannesburg.

It should also be noted that the participants in my study were predominantly low-income innercity dwellers. However, further studies may be necessary to understand the dynamics of this observation better.

With the above, the empirical and theoretical findings of this PhD concerning the oral health needs and determinants of the OHRQoL of the HIV infected adolescents in Johannesburg, are illustrated in the adapted conceptual framework in Fig 8.1 below. Oral health perceptions are at the second-dimensional level, where they influence the 'individual's' (first level dimension) oral-health-related quality of life. When unpacking the 'individual' and 'environment' dimensions, different factors came out of the SA study (Bold italic white), similar to the original framework but different from the rest of Africa (Underlined).



Fig. 8.1: Oral health needs and determinants of the oral-health-related quality of life of the HIV infected adolescents in Johannesburg

In all, OHRQoL does not exist in isolation but is influenced by an interplay of socioeconomical, biological, and personal psychosocial risk factors and the HIV infection trajectory. A comprehension of these interplay and framework of OHRQoL will begin a process to 172 manage the OHRQoL impacts. Consequently, OHRQoL measures go beyond measuring medical outcomes, such as signs and symptoms but also measures psychological, socioeconomical outcomes, health services utilisation and health-seeking behaviour.

8.3 CONCLUSIONS

This study aimed to assess the oral health needs and the oral-health-related quality of life of adolescents living with HIV in the Johannesburg setting. The essential conclusions from this study are the following. There was a high prevalence of dental caries and oral mucosal lesions among ALHIV in Johannesburg. The reported prevalence was associated with high HIV RNA viral loads, low CD4 cell count and high WHO staging of HIV disease. Additionally, caries experience contributed to the prevalence of OML. Our study acknowledges the protective effect of HIV treatment and positive oral health practices on the presence of oral conditions among ALHIV in care at the Wellness Centre in Johannesburg. However, the burden of soft tissue lesions is still present in the face of long-term antiretroviral treatment, albeit a different pattern and lower prevalence. The immune status of the patients may influence the presence of oral diseases.

The current oral mucosal lesions pattern has the potential to perpetuate the self-stigmatisation and self-isolation due to the self-perceived mouth symptoms such as bad breath, pain, teeth staining, ulceration and bleeding. As a result, perceptions and experiences of OHRQoL among ALHIV in Johannesburg were influenced by a combination of self-perception and social connections, together with the state of their structural environment and biological wellbeing.

With regard to the oral-health-related quality of life of the adolescents, the participants placed a higher value on coping, symptom endurance and dental facility service experiences as determinants of OHRQoL. The coping dimension that came out strong from the in-depth exploration may explain the unexpected finding that the ALHIV reported fewer impacts than those from the school group generally; despite the high burden of lesions in the teeth and mouth. Lesser impact means they are resilient or cope with their oral conditions. There were, however, nuances related to the stigma from the ALHIV perceptions, experiences, and oral disease impacts could be interrelated. Issues related to coping and resilience were evident; they must be monitored to prevent the worsening of dental decay and concomitant symptoms and effects. Risk-based monitoring maybe is useful in this regard. The new dimensions added to the tool to produce additional dimensions not otherwise found in the original COHIP tool and resulted in the adjusted oral-health-related quality of life tool.

The modified oral-health-related quality of life tool displayed acceptable initial reliability and validity. These were the dimensions relevant to the Johannesburg setting and context. The tool displayed discordance of the observed and the expressed signs and symptoms of oral diseases with the OHRQoL outcomes. The adolescents' OHRQoL scores were related to the high-untreated caries, toothache reports, a poor self-rated oral health and being in schools. It is, thus, advisable that before a measurement tool is used for the first time in a context and different type of participants, it should be validated and tested for applicability to that context. Additional studies are, nonetheless, suggested to retest the new tool with contextual sub-scales.

SCHOLARLY CONTRIBUTION

This PhD study contributed to knowledge in the field of adolescent oral health care and HIV in South Africa and regionally. The study resulted in one of the first systematic reviews in Africa on factors influencing the oral-health-related quality of life in children in the African setting. The review provided further insight on the applicability of OHRQoL conceptual frameworks in the African setting; the SA, specifically urban Johannesburg contextual distinctiveness became evident. As there were no South African studies published at the time of the review, contrasting the results of the current study with the review informed us of the other factors influencing OHRQoL not seen in the review in other African countries but from the SA, Johannesburg study. It thus seems the Johannesburg setting may respond similarly to developed countries. However, this warrants further exploration.

The adolescents' experiences and perceptions of conditions' study provided an essential methodological contribution by the mixed-methods design and using a comparator group to place the results in context unlike presenting a one-sided aspect of a cohort of HIV infected adolescents. The participants, particularly ALHIV, placed a high value on oral health functioning coping ability, symptom endurance and self-assigned isolation.

The study provided an epidemiological update of the oral lesions in the adolescent population infected with HIV, wherewith future research could lie. The South African setting now has baseline data on oral health care among the adolescents living with HIV. The study highlights the presence of unmet oral care needs among those virally suppressed amidst the positive role

of antiretroviral treatment. In all, the results provide essential information to be taken into account in the multidisciplinary care services of the adolescent population living with HIV in the Johannesburg setting.

8.4 RECOMMENDATIONS FROM THE PHD STUDIES

The following are the programme, policy recommendations together with training and future research recommendations from this study.

8.4.1 Recommendations for Practice and Programme Implementation

There is a need for targeted adolescents' oral health programmes to deal with pockets of unmet oral health needs. Such intervention should not be at the expense of other interventions or priority groups. For instance, adolescents are often neglected by school oral health programmes potentially due to the over-emphasis on primary teeth in the primary school programmes. This tendency may be the cause of our observed generally poor oral health status of adolescents.

Continuous oral health education is recommended for adolescents potentially through youthfriendly platforms such as the use of technology eMobile education applications. The education will promote a positive oral health behaviour and can be used to facilitate access to services.

There is a need to improve the prioritisation and provision of oral health support services for adolescents in Johannesburg. The study also highlighted that for the adolescents in Johannesburg, there were observed service complaints with dental services acquired.

Promoting treatment adherence among ALHIV, routine screening at every contact, and effective management are essential to preventing the progression of oral diseases.

There is a need to include an oral health care package in the Wellness clinics. Appropriate tools and job aids should be developed to promote greater integration of oral care into other adolescents' health services.

8.4.2 Recommendations for Policy

HIV management guidelines and treatment protocols should include oral care and impacts of oral diseases as part of their overall integrated health care and wellbeing in these settings.

The OHRQoL tools should be routinely used to assess oral health needs and should form part of scheduled oral health surveys.

There is a need for greater collaboration between relevant government departments, such as the Department of Education and Health, to promote oral health among adolescents through school health programmes.

8.4.3Training of Oral Health Practitioners

Incorporate the socio-dental indicators in the form of oral-health-related quality of life indices in training all categories of undergraduate oral health practitioners.

8.4.4 Future Research

It is recommended that oral-health-related quality life assessments should be part of oral health surveys. For example, local, provincial, and national oral health stakeholders should be engaged to incorporate socio-dental indices when collecting clinical data.

The distribution of dental caries by socio-demographic characteristics will require further exploration in future studies. Further probing is required as the study leaves questions on the parental employment influence on the adolescents' disease burden.

The ALHIV are a population where broader overarching issues such living with the infection, impact so much on their lives. Furthermore, the disclosure in this stage in life is such that they learn to be accustomed to some symptoms, perhaps to have high endurance levels and internalise them. Therefore, there is a need to explore the concept of coping, closely related to the resilience of oral symptoms among adolescents in more detail.

Longitudinal studies ought to be conducted to look at COHIP sensitivity in the setting/culture, as well as, age, sex and SES influences in larger multi-centre studies within the Gauteng province or multiple provinces.

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APPENDIX 1: Information Leaflet and Assent Form for Adolescents

Assent form for Study Topic: Oral health Needs and oral-health-related quality of life of adolescents

Hello

This letter is to tell you about the study we like you to be a part of. Our team led by Dr Kolisa (011 717 2247; <u>yolanda.kolisa@wits.ac.za</u>) from the dental clinic are doing a study on the **"Oral health Needs and oral-health-related quality of life of adolescents"**.

What is needed from you?

The study involves you answering questions about your teeth and mouth and how they affect the way you live your life.

- We will ask you questions, fill in the form with your answers.
- We will ask to have a detailed interview/talk with you which might last about 45-60 minutes. The notes will be taken during the interview and the answers will also be tape recorded, if you agree.
- We will do a check-up in your mouth. Doing a mouth check-up is not painful.
- For the hospital patients, we will also look at your medical file and record medical information.

No names

No-one will force you to carry on. No-one will be cross or upset with you if you don't want to.

The form will have no names and the one with name will be kept safe and used by the research team only. When it is used no names will be reported.

Benefits

There are no direct benefits for you right now but the results of the study will help all the managers of the health services to change and address the concerns about quality of life related to oral problems in our clinics.

Risks

There are no risk from taking part in the study. No sensitive questions will be asked however, if you are asked questions you are not at ease to answer, you may not answer them and that will not be held against you.

Free to stop anytime

If you do not want to take part any more, you may decide at any time during the study not to carry on; even after you first agreed to be part of the study.

What will happen after the check-up?

If we find that you need dental treatment, you will get oral health education and get treatment if urgent, otherwise you will be given an appointment to come for treatment. If you do not require any dental treatment, you will get oral health education. If we cannot provide treatment to you in this clinic, we will refer you to the Wits Oral Health Centre.

Your parent/guardian(s) are aware of what I am doing and I have also asked for their permission to look into your mouth, but I will not do this if you do not want me to. You are free to say "yes" or "no", and if you are not sure, you can ask me any questions. For any concerns, questions and complaints about the study, please contact the Wits HREC offices: Prof P Cleaton-Jones, Tel: 011 717 2301 or <u>peter.cleaton-jones1@wits.ac.za</u> OR Ms Z Ndlovu 011 717 2700/1234/1252; <u>zanele.ndlovu@wits.ac.za</u>

Would you like be in the study? Yes No

(Circle the response given)

	Your name	Person Obtaining	Parent / Guardian / Nurse As
		Consent	Witness
Name :[Please			
Print]			
Signature:			

APPENDIX 2: Information Leaflet and Informed Consent by Parent/Guardian on Behalf of their Children

Topic of Study: Oral health needs and oral-health-related quality of life of adolescents

Dear Parent /guardian

We would like to invite your child to be part of a study done in this school/clinic. This letter will help you to decide if you want your child to be part of the study. If you have any questions that this letter does not fully explain, **please ask me, Dr Kolisa: 011 717 2247 OR 0837800907**. Email: <u>yolanda.kolisa@wits.ac.za</u>

What are we going to do? The study will ask information from your child about anything related to their teeth and mouth. We will ask questions, fill in the form with their answers, record/audiotape their answers and then we will do a dental check-up in their mouth. For the hospital patients, we will also look at your child's medical file. Checking the mouth is not painful. Should they need dental treatment, they will get an appointment for treatment at this clinic or the referral letter to the Wits Oral Health Centre. Why are we doing the study? We are doing the study to collect information on the children's feelings, needs from having dental problems. We want their own views on how it feels to have teeth and mouth problems [if they do]. If they do not, what did they do not to have mouth problems? This knowledge will help us to know how they are affected by dental problems so that we can plan the services suiting their needs.

Will it be harmful to the child? There will be no harm to your child if they are part of the study. We are going to ask them questions which are not hurting. They may not answer if they feel unsure or uncomfortable.

Will the children benefit from the study? : The children will get chance to talk about their mouth problems. The results of the study will enable us to plan and rethink about how dental services are available for the children especially in your area.

Your rights as a participant: Your child's /dependent participation in this study is entirely at free will and no name will be required in the questionnaire. You can refuse to participate in the study without giving any reason. Your withdrawal will not affect you or your child's education or treatment. **Confidentiality:** All information that you give will be kept strictly confidential. When we are finished with the study the research reports will have no names.

Ethical approval: This study has been allowed and found to be ok by the Human Research Ethics Committee (HREC) of the Faculty of Health Sciences at Wits University. For any concerns, questions and complaints about the study please contact the Wits HREC offices: Prof P Cleaton-Jones, Tel: 011 717 2301 or peter.cleaton-jones1@wits.ac.za OR Ms Z Ndlovu 011 717 2700/1234/1252; zanele.ndlovu@wits.ac.za

Agree to participate in this study

I agree that the person asking my permission for my child to take part in this study has told me what the study is about and how it will be done. I have also read and understood the information about the study. I am aware that the results of the study and the final report will not include names or file numbers. I have had time to ask questions and have no problem to be part of the study. I understand that I will not be punished if I want to stop being in the study.

Parent/Guardian(s) Name	•••
(Please print)	

Parent/Guardian(s) Signature......Date.....Date.....

APPENDIX 3: Clinical Data Capture Sheet with WHO DMFT Index

STUDY RANDOM CODE:

Decayed-Missing-Filled Index (DMF) which was introduced by Klein, Palmer and Knutson in 1938 and modified by WHO:

The DMF teeth index (DMFT) which measures the prevalence of dental caries/Teeth. The components are:

<u>D</u> component: Used to describe (Decayed teeth) which include: Carious tooth; Defect filling with caries; Temporary filling.

<u>M</u> component: Used to describe (Missing teeth due to caries)

<u>F</u> component: Used to describe (Filled teeth due to caries).

Permanent teeth	18	17	16	15	14	13	12	11	21	22	23	24	25	26	27	28
Status																
Treatment																
Permanent teeth	48	47	46	45	44	43	42	41	31	32	33	34	35	36	37	38
Status																
Treatment																

DENTITION STATUS AND TREATMENT NEEDED

TREATMENT

0 = None

STATUS:

0 =Sound

1 = Decayed

2 = Filled and Decayed

4 = Missing due to caries

5 = Missing for other reasons

7 = Bridge abutment/special

3 = Filled, no decay

6 = Sealant/varnish

8 = Un-erupted tooth

crown

Summary of dental status:

D – decayed, M-missing - F-filled

1 = Caries arresting or sealant

care

- 2 = One surface filling
- 3 = Two or more surface filling
 - 4 = Crown and bridge abutment
 - 5 = Bridge element
- 6 = Pulp care
 - 7 = Extraction

.

8 = Need for other care

DMFT/dmft

D/d

M/m

F/f

APPENDIX 4: Data Capture Sheet with OHARA Case Definitions

Random generated number						Grade	in school		
Age									
Gender		М		F					
Parents age									
Parents sex						Parents	employment statu	IS	
In general, how would you rate th <u>mouth</u> ?	e health	of your <u>teeth and</u>	1=Poor		2=Fair	1	3=Good	4=Very good	5=Excellent
Do you think you need dental trea months?	atment w	vithin the next 3	1=Stron Disagre	gly e	2=Disa	agree	3=Undecided	4=Agree	5=Strongly Agree
Are you satisfied with the condition	on of you	ur <u>teeth or mouth?</u>	1=Not Satisfied	d	2=Moo Satisfi	derately ed	3=Satisfied	4=More Satisfied	5=A Lot Satisfied
Have you been to a dentist in the j school dental services)?	past 6 m	onths (exclude the	1=Yes		2=No				
In the past 3 months, how often do	o you br	ush your teeth?	Never		Once a Month	a 1	Once a Week	Once a Day	Twice a Day
ART start Date									
Duration of ART (DART) (in mon	ths,								
Viral loads									
CD4+ lymphocyte count			1						
WHO staging									
D/d									
M/m									
F/f									
DMFT/dmft									
OHARA CASE DEFINITIONS					1		ſ	Γ	ſ
Fungal lesions	1				Viral l	esions			
	01	Pseudomembranous	candidia	sis	04	Hairy l	eukoplakia		

	02	Erythematous candidiasis	05	Oral wart
	03	Angular cheilitis	06	Herpes labialis
			07 Recurrent intraoral herpes simplex	
Idiopathic			Neopl	asms
	08	Recurrent aphthous stomatitis	11	Oral Kaposi sarcoma
	09	Non-specific Ulceration NOS	12	Oral non-Hodgkins lymphoma
	10	Linear gingival erythema	13	Oral squamous cell carcinoma

APPENDIX 5: OHARA Case Definitions

Table 1 Case definition algorithm summarizing clinical descriptors, symptoms, and duration for common HIV-related oral mucosal lesions

								Biopsy
Etiology	Oral Lesion/ condition	Color	Character	Extent	Location	Symptoms	Duration	Required
				Localised or				
Fungal	Pseudomembranou	sWhite Yellow	Plaques (usually	generalised	Anywhere	None to mild	Intermittent	No
Infections	Candidiasis	Creamy	removable)					
	Erythematous			Localised or	Palate dorsum of			
	candidiasis	Red	Flat patchy	generalised	tongue buccal mucosa	None to mild	Intermittent	No
			Fissured	Unilateral or				
	Angular cheilitis	Red White	ulcerated	bilateral	Lip commissures	None to mild	Intermittent	No
				Unilateral or				
Viral	Hairy leukoplakia	White	Corrugated	bilateral	Lateral tongue	None	Longstanding	g No
			Raised smooth					
Infections	Oral wart	White mucosa	lspiky	Solitary or multipl	eAnywhere	None	Longstanding	g Yes
			cauliflower-like	clustered				

	Recurrent herpes labialis	Red mucosal	Vesicular (vesicles)	Solitary or clustered	Vermillion border (lip)	Mild to moderate	Intermittent	No
			ulcerated				7–10 days/	
			Vesicular		Gingiva hard	Mild to	epibode	
	Recurrent intraoral	Red mucosal	(vesicles)	Clustered	palate	moderate	Intermittent 7–10 days/	No
	herpes simplex		ulcerated				episode	
						Moderate to		
Idiopathic	Recurrent aphthous	White Yellow	Ulcerated	Solitary or multipl	eLabial mucosa,	severe	Intermittent Minor: 7–	No
Conditions	Stomatitis				buccal mucosa, ventral tongue		10 days	
					floor of		Major: weeks History of	
					mouth soft palate		recurrence	
	Ulceration NOS/		Ulcerated		1			
	necrotizing ulcerative stomatitis	White Yellow	necrotic	Solitary (>1 ulcer may be present)	Anywhere	Severe	Longstanding	Yes
	Necrotizing	Red Soft	Necrotic Fetid					
Bacterial	ulcerative gingivitis or	palate	odor	Localised	Gingiva and	Severe	Sudden onset	No
Infections	periodontitis	White Yellow		or generalised	underlying bone			
	Oral Kaposi		Flat/macular		Anywhere	None to		
Neoplasm	ssarcoma	Red Purple	raised	Solitary	predilection for	moderate	Longstanding.	Yes
			nodular ulcerated		palate and gingiva			
					Anywhere	None to		
	Oral non-Hodgkin's	s Red White	Raised ulcerated	dSolitary	predilection for fauces, palate,	moderate	Longstanding	Yes
	Lymphoma		indurated		gingiva			

Oral squamous cel	1		Anywhere			
carcinoma	Red White	Raised ulcerated Solitary	predilection for	None to severe Longstanding	•	Yes
		indurated	tongue			

APPENDIX 6: Human Research Ethics Committee Clearance Certificate



R14/49 Dr Yolanda Kolisa

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M161142

NAME: (Principal Investigator)	Dr Yolanda Kolisa
DEPARTMENT:	Community Dentistry Charlotte Maxeke Johannesburg Academic Hospital Diepsloot Outreach Site
PROJECT TITLE:	Oral Health Related Quality of Life and Oral Health Needs of HIV-Infected Adolescents in Johannesburg
DATE CONSIDERED:	25/11/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr J. Igumbor
APPROVED BY:	Uliasfaces
	Professor P. Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	08/03/2017
This clearance certificate is va	alid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004,10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit to the Committee. <u>Lagree to submit a yearly progress report</u>. The date for annual re-certification will be one year after the date of convened meeting where the study was initially review in November and will therefore be due in the month of November each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX 7a: JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies

Reviewer	Date	

Author _____Year____Record Number_____

		Yes	No	Unclear	Not			
					applicable			
1.	Were the criteria for inclusion in the sample clearly			_				
	defined?							
2.	Were the study subjects and the setting described in detail?							
3.	Was the exposure measured in a valid and reliable way?							
4.	Were objective, standard criteria used for measurement of							
	the condition?							
5.	Were confounding factors identified?							
6.	Were strategies to deal with confounding factors stated?							
7.	Were the outcomes measured in a valid and reliable way?							
8.	Was appropriate statistical analysis used?							
Ove	rall appraisal: Include 🗆 Exclude 🗆 Seek fur	ther info						
Con	Comments (Including reason for exclusion)							

APPENDIX 7b: JBI Critical Appraisal Checklist for Cohort Studies

Reviewer	Date	
Author	Year	Record Number

		Yes	No	Unclear	Not
					applicable
1.	Were the groups similar and recruited from the same population?				
2.	Were the exposures measured similarly to assign people to both exposed and unexposed groups?				
3.	Was the exposure measured in a valid and reliable way?				
4.	Were confounding factors identified?				
5.	Were strategies to deal with confounding factors stated?				
6.	Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?				
7.	Were the outcomes measured in a valid and reliable way?				
8.	Was the follow up time reported and sufficient to belong enough for outcomes to occur?				
9.	Was follow up complete, and if not, were the reasons for loss to follow up described and explored?				
10.	Were strategies to address incomplete follow up utilized?				
11.	Was appropriate statistical analysis used?				
Overall appraisal: Include Exclude Seek further info Comments (Including reason for exclusion)					

Rev	iewerDate				
Aut	horYear		_Record	Number	
		Yes	No	Unclear	Not applicable
1.	Was the sample frame appropriate to address the target population?				
2.	Were study participants sampled in an appropriate way?				
3.	Was the sample size adequate?				
4.	Were the study subjects and the setting described in detail?				
5.	Was the data analysis conducted with sufficient coverage of the identified sample?				
6.	Were valid methods used for the identification of the condition?				
7.	Was the condition measured in a standard, reliable way for all participants?				
8.	Was there appropriate statistical analysis?				
9.	Was the response rate adequate, and if not, was the low response rate managed appropriately?				
Ove	rall appraisal: Include 🗆 Exclude 🗆 Seek fur	ther in	fo □		

APPENDIX 7c: JBI Critical Appraisal Checklist for Studies Reporting Prevalence Data

Comments (Including reason for exclusion)

AuthorYearRecord Number Yes No Unclear N 1. Is there congruity between the stated philosophical perspective and the research methodology? Image: Congruity between the research methodology and the research question or objectives? Image: Congruity between the research methodology and the research question or objectives? Image: Congruity between the research methodology and the methods used to collect data? Image: Congruity between the research methodology and the representation and analysis of data? Image: Congruity between the research methodology and the interpretation of results? Image: Congruity between the research methodology and the interpretation of results? Image: Congruity between the research methodology and the interpretation of results? Image: Congruity between the research methodology and the interpretation of results? Image: Congruity between the research methodology and the interpretation of results? Image: Congruity between the research research and vice- versa, addressed? Image: Congruity between the research research, and vice- versa, addressed? Image: Congruity between the research research, and vice- versa, addressed? Image: Congruity between the research and vice- versa, addressed? Image: Congruity between the research research, and vice- versa, addressed? Image: Congruity between the research research, and vice- versa, addressed? Image: Congruity between the research research, and vice- versa, addressed? Image: Congruity between the research research, and vice- versa, addressed? Image: Congruity between the research research research research research research resea	ReviewerDate_					
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 3. Is there congruity between the research methodology and the methods used to collect data? 4. Is there congruity between the research methodology and the representation and analysis of data? 5. Is there congruity between the research methodology and the interpretation of results? 6. Is there a statement locating the researcher culturally or theoretically? 7. Is the influence of the researcher on the research, and vice- versa, addressed? 8. Are participants, and their voices, adequately represented? 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? 10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data? 	2.	Is there congruity between the research methodology and the research question or objectives?				
 4. Is there congruity between the research methodology and the representation and analysis of data? 5. Is there congruity between the research methodology and the interpretation of results? 6. Is there a statement locating the researcher culturally or theoretically? 7. Is the influence of the researcher on the research, and vice- versa, addressed? 8. Are participants, and their voices, adequately represented? 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? 10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data? 	3.	Is there congruity between the research methodology and the methods used to collect data?				
 5. Is there congruity between the research methodology and the interpretation of results? 6. Is there a statement locating the researcher culturally or theoretically? 7. Is the influence of the researcher on the research, and vice- versa, addressed? 8. Are participants, and their voices, adequately represented? 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? 10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data? 	4.	Is there congruity between the research methodology and the representation and analysis of data?				
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 7. Is the influence of the researcher on the research, and vice- versa, addressed? 8. Are participants, and their voices, adequately represented? 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? 10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data? 	6.	Is there a statement locating the researcher culturally or theoretically?				
 8. Are participants, and their voices, adequately represented? 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? 10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data? 	7.	Is the influence of the researcher on the research, and vice- versa, addressed?				
 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval □ □ □ □ 10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data? 	8.	Are participants, and their voices, adequately represented?				
by an appropriate body? 10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data?	9.	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval				
	10.	by an appropriate body? Do the conclusions drawn in the research report flow				
Overall appraisal: Include Exclude Seek further info Comments (Including reason for exclusion)	Overa Comm	from the analysis, of interpretation, of the data? Il appraisal: Include 🗆 Exclude 🗆 Seek f nents (Including reason for exclusion)	urther ir	nfo 🗆		

APPENDIX 7d: JBI Critical Appraisal Checklist for Qualitative Research

APPENDIX 8: Data extraction template for retrieved publications (Systematic review)

Quality of life , Oral Health , Child, Determinants				
Author				
Title				
Publication Date				
Study Design				
Sample Size				
Participants	Children or Parents proxy for children			
Intervention				
Conceptual				
Framework /Model				
Specified				
Outcome				
Or Tool Used				
Determinants				
APPENDIX 9: The Interview Guide

The original theme guide included the following issues:

- Thoughts about teeth in general;
- Thoughts about one's own teeth and their appearance;
- If and how teeth could affect oneself in their daily activities;
- Ideas and wishes regarding the looks of the teeth and reflections on what affected these views;
- Issues of concern regarding teeth in relation to friends and family, and society in general, including school life

The interview guide was structured to cover matters of oral health and quality of life among adolescents.

- 9. What can you tell me about your teeth and mouth? Probe more 'Tell me more...
- 10. What can you tell me about your teeth and mouth and role in everyday activities? Probe more 'Tell me more...
- 11. How do you feel about your mouth and teeth? Probe more "anything else you want to say?"
- 12. Why do you feel that way?
- 13. What importance do you place in your teeth and mouth?
- 14. What are your experiences from visiting a dentist/dental hospital?'
- 15. Adolescents were encouraged to expand on their replies and probed further by asking: 'Tell me more..; how do you feel...;'

APPENDIX 10: Modified Child Oral Health Impact Profile (C-OHIP) in SA Context

UNIVERSITY OF THE	Questionnaire: Modified Child Oral		FACULTY OF
WITWATERSRAND, 🍣 Johannesburg	Health Impact Profile (C-OHIP) in		HEALTH SCIENCES
	SA Context		
Ago	Sov: Malo F	amala	PLEASE TCIK 🗸
Age		emaie	5
Grade in school	Residence/Location		

Parent employment: Self-Employed ____ Employed ____ Unemployed _____

Before you answer, ask yourself: Does this happen because of my teeth, mouth, and face? Choose the answer that best describes you in the past 3 months

Original five dimensions: oral health, functional wellbeing, socio-emotional wellbeing, school performance and self-image.

ITEMS	Never	Never	Almost	Sometimes	Fairly Often	Time	All the
1. Had pain in your teeth/toothache.							
2. Had crooked teeth or spaces between your teeth.							
3. Had discoloured teeth or spots on your teeth.							
4. Had bad breath.							
5. Had bleeding gums							
6. Been unhappy or sad							
7. Missed school for any reason because of your teeth							
8. Been confident because of your teeth							
9. Had difficulty eating foods you would want							
10. Felt worried or anxious							
11. Not wanted to speak/read out loud							
12. Avoided smiling or laughing							
13. Had trouble sleeping							
14. Been teased, bullied							

15. Felt that you were attractive					
16. Felt that you look different					
17. Had difficulty saying certain words					
18. Had difficulty keeping your teeth clean					
19. Been worried about what other people think					
20.Had a problem with getting dental care because the					
clinic/hospital is far					
21.Had problem with getting dental care because my					
parents/caregivers are usually at work					
22.Had a problem with getting dental care because my					
family cannot afford					
23.Had a problem with getting dental care because the					
clinics are closed					
24.At the dental clinic, they do not take my teeth and mouth					
complains seriously					
25.At the dental clinic, they do not address my teeth and					
mouth problems when I complain, instead they focus on					
other issues					
26.Treatments of mouth and teeth problems are too painful					
27.If I have a problem with my teeth or mouth, I do not tell					
anybody					
28.I do nothing when I have pain in my mouth					
29.I do not know what to do when I have pain					
	Po	Fai	Av	Go	Ex
	or	r	erag	od	celler
30.Overall, please rate your oral health			CO CO		ht

Source of original COHIP Tool - With permission from Dr. Hillary L. Broder, Cariology and Comprehensive Care, NYU, 380 2nd Av, Suite 301, New York, NY 10010. Tel.: 212-998-9806; Fax: 212-995-4912; email: hillary.broder@nyu.edu. Hillary L. Broder and Lacey Sischo are with the Cariology and Comprehensive Care, NYU. Maureen Wilson-Genderson is with the Department of Social and Behavioural Health, VCU School of Medicine.