

# 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

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## SUMMARY

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.

This study assessed an existing tool by exploring the perceptions and experiences of OHRQoL among adolescents living with HIV (ALHIV) in Johannesburg.

Twenty-five in-depth-interviews of both ALHIV and HIV-undiagnosed adolescents were conducted and thematically analysed to identify arising themes.

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## ACRONYMS

<b>ALHIV:</b>	Adolescents Living with HIV
<b>COHIP:</b>	Child Oral Health Impact Profile
<b>OHRQoL:</b>	Oral Health-Related Quality of Life
<b>IDIs:</b>	In-Depth Interviews

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.

The perceptions and experiences of OHRQoL among ALHIV in Johannesburg were influenced, as elsewhere, by a combination of self-perception and social interactions, 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.

## Keywords

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

## INTRODUCTION

According to global reports, there are nearly 2.1 million adolescents (10-19 years) living with HIV Infections (ALHIV).<sup>1</sup> 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.<sup>2</sup>

ALHIV remain vulnerable to oral diseases<sup>3</sup> and have high unmet oral health care needs despite their regular use of anti-retroviral treatment (ART) services.<sup>4,5</sup> 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.<sup>6-8</sup> This may or may not be the case for South Africa given that OHRQoL varies with socio-cultural and economic factors.<sup>9,10</sup>

Oral health influences people physically and psychologically; 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.<sup>11</sup>

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 crano-facial complex".<sup>12</sup>

The conceptualisation of OHRQoL is context reliant as it highlights social relationships in a social environment.<sup>9</sup> Koot and Wallander (2002) added that health-related quality of life has dual subjective-objective elements underpinned by the phase in one's life.<sup>13</sup>

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, self-image and social acceptance.<sup>15,16</sup> 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.<sup>17,18</sup> 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.<sup>19</sup>

Sischo and Broder proposed in their 'Theoretical Model of OHRQoL' that the biological-symptom-functional status complex of oral conditions is directly driven by both individual and environmental characteristics and these overall exert an influence on OHRQoL.<sup>20</sup> However, various scholars in the field argue that the frameworks

and models consistently underscore the importance of the socio-cultural context and its complex interplay with other critical determinants of OHRQoL.<sup>21,22</sup>

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.<sup>20</sup>

## 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.<sup>22</sup>

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.<sup>23</sup> 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.<sup>20,21</sup>

Twenty-five adolescents, 14 females and 11 males ranging from 14 to 19 year olds (Table 1) participated in the IDIs until no new information was retrieved.

**Table 1.** Distribution of participants

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

## 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 1).



**Figure 1.** Domains and themes identified from the transcripts.

### Individual-level domain

#### 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.

#### 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, Wellness site)*

### 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, but usually, I would do it twice."* (Female 16 years, Wellness site)

### 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 feel .....not sure.....but now I am used to chewing on one side."* (Female 15 years, School)

### External factor domain

#### 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 sorcer, so there was definitely no turning back."* (Female 16 years, Wellness site)

### 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 past 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 attend well, and 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 checkup 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)

### Social impact domain

#### 1. Interpersonal relationships and social support

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 well being 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)*

#### 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.

### 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.<sup>12</sup>

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.<sup>21</sup>

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.<sup>24</sup>

A Brazilian study added that females are more sensitive to physical appearance during adolescence compared with their male contemporaries.<sup>25</sup> 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.<sup>5-8,26</sup>

Experiencing oral health symptoms and functional difficulties resulted in the adoption of self-care 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.<sup>27</sup>

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.<sup>27</sup> 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 socio-economic reasons.

Conceptually, access to oral health care is an important determinant both at the individual and family level.<sup>21,20</sup> Access to health services influences oral healthcare-seeking behaviour and, by extension, oral health well-being. 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.<sup>28</sup> 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.<sup>29</sup> This theme was more common among ALHIV due to negative labelling arising from internalised shame associated with the causes of the HIV infection.<sup>30,31</sup> 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.<sup>20</sup>

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.<sup>20</sup> The interaction between biomedical and psychosocial dimensions and constructs of OHRQoL is also present in a model proposed in 2005.<sup>32</sup>

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.<sup>27</sup>

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.<sup>5</sup> The study also re-emphasizes the need to intensify general health services re-sensitisation for more adolescent and youth friendliness.

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