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# Perceptions on causes and effects of common oral diseases among HIV-positive and HIV-negative adults in Kigali, Rwanda: a qualitative study

Julienne Murererehe[1,2*], Yolanda Malele-Kolisa[2], Aimable Musafili[3] and Veerasamy Yengopal[4]

## Abstract

**Introduction** Exploring perceptions of oral health can influence the design of interventions to prevent common oral diseases and contribute to quality dental care of patients. There is lack of qualitative studies that explored patients' perceptions regarding possible causes and effect of oral diseases in Rwanda.

**Aim** The study aimed to explore perceptions on causes and effect of oral disease among HIV-positive and HIV-negative adults at Kigali, Rwanda.

**Method** A qualitative study design using in-depth interviews (IDIs) were conducted among 21 patients with caries and or periodontal diseases including 10 HIV-positive and 11 HIV-negative adults from the HIV clinic of Kigali Teaching Hospital (CHUK). The interview was conducted in Kinyarwanda using an interview guide. The audio recording was done for subsequent data analyses. Thematic content analysis was used to analyze the data using an inductive approach. NVivo software version 11 was used to code and organize the data.

**Results** Two broad domains and six themes emerged from the results. The first broad domain was "perceptions on causes of oral diseases" with two themes (individuals and external factors). The second broad domain was "perceptions on oral diseases effect" with 3 themes (physical or functional effect, psychological effect and social effect). Interviewees perceived individuals' factors (diet, lack of oral hygiene, older age, delayed dental visit, negligence, lack of knowledge, poverty, heredity) as possible causes for their oral diseases. In addition, HIV-positive participants perceived antiretroviral treatment and HIV infection among the possible causes for their caries and periodontal disease. The reported perceptions on oral diseases effect were physical or functional effects (affected appearance, eating difficulty, pain, difficulty smiling or laughing); psychological effects (heartbreak, being annoyed, feeling inferior, anxiety, being unhappy, being worried, hopelessness) and social effects (avoidance or self-isolation, shame or embarrassment and exposure to mockeries). The summary patterns on perceptions of oral diseases showed more frequency of HIV-positive interviewees reporting physical or functional effect and psychological effects compared to HIV-negative counterparts.

*Correspondence:
Julienne Murererehe
j.murererehe@ur.ac.rw

Full list of author information is available at the end of the article

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**Conclusion** Interventions are needed to prevent caries and periodontal diseases and their effects by tackling various individual, external factors thereby limiting physical, psychological and social effect associated with oral diseases. More attention should be given to high-risk group of HIV-positive people.

**Keywords** Perceptions, Possible causes, Common oral diseases, HIV, Adults, Rwanda

## Introduction

Oral diseases, mostly caries and periodontal diseases, are associated with various problems, including tooth loss, incapability to masticate or eat properly, adverse effects on systemic health, affected aesthetics, limited suffers' ability to attend work or perform well in school, compromised psychological well-being and economy of affected people [1–3]. There is a paucity of literature exploring patients' perceptions on possible causes and effect of oral diseases generally and in Rwanda [1]. Assessing these perceptions can influence the design of interventions to contribute to quality dental care and improved quality of life of affected individuals.

Caries and periodontal diseases are prevalent, severe, and challenging to manage among people generally and those living with other chronic diseases, including HIV-positive people [4]. On the other hand, controversies exist in the published research on possible causes contributing to the higher prevalence of common oral diseases among HIV-positive persons compared to HIV-negative counterparts [5].

In Rwanda, especially, studies on oral disease are generally scarce. Also, few published studies on dental caries and periodontal diseases in Rwanda revealed a high prevalence of dental caries and periodontal diseases. For instance, a study by Janvière and colleagues in Rwanda military hospital revealed a high prevalence of periodontal disease among participants [6]. In their research, HIV infection was one of the systemic diseases associated with periodontal diseases [6]. In addition, recent comparative studies revealed a higher prevalence of periodontal diseases [7] and dental caries [8] among HIV-positive people than HIV-negative counterparts in Rwanda.

Nevertheless, most studies done on this matter used quantitative approaches. This is the first study in Rwanda to consider a qualitative approach to understanding patients' perceptions on possible causes and effect of caries and periodontal diseases Understanding patients' perceptions on possible causes and effect of caries and periodontal diseases will help plan interventions to improve oral health and general health among the Rwandan population, especially those living with HIV infection. This qualitative study can also reveal new or contextual possible causes and perceptions regarding oral diseases that could not easily be discovered through the quantitative approach. Hence, this study aimed to explore perceptions on causes and effect common oral diseases among HIV-positive and HIV-negative adults at an HIV clinic of CHUK Rwanda.

## Methods

### Study setting

The study was conducted from an HIV clinic of Kigali teaching hospital (CHUK) located in Kigali city. CHUK is located in the capital City of Rwanda but since CHUK is a referral hospital it also receives both urban and rural populations with diverse believes, perceptions and lifestyles. For this study, HIV negative participants were obtained from people who visited HIV clinic for voluntary testing. Those whose HIV tests became negative were informed about our study by their nurses who in turn oriented those interested to data collectors informed consent.

### Population

The study population was HIV-positive and HIV-negative adults (aged 18 years and above) diagnosed with dental caries and/or periodontal diseases. Participants who did not want their interviews to be audio-recorded and those without caries and/or periodontal diseases were excluded from the study.

### Sampling techniques

Participants with diseases of interest (caries and periodontal diseases) were purposively recruited from the initial sample obtained through doing oral diagnosis at the recruitment level in the HIV clinic of CHUK. This manuscript is part of a bigger project on status and factors for caries and periodontal diseases. Purposive sampling for recruitment was carried out until data saturation was achieved and no new information appeared. The data saturation was reached after 10 in-depth interviews with HIV-positive individuals and 11 HIV-negative persons.

### Inclusion criteria

Only participants with caries and/ or periodontal diseases, aged 18 and more were purposively recruited for this study. The following inclusion criteria were considered to ensure diversity: HIV-positive vs. HIV-negative; young adults 18–30 years old vs. 31 and above and Males vs. females.

### Data collection method and instrument

In-depth interviews (IDIs) were used to collect information related to the study objective. IDIs were chosen

because they are effective in getting respondents talking about their personal experiences, feelings, and opinions [9]. In addition, respondents feel more relaxed and confident to express sincerely what they think about a given subject individually [9]. Interviewees were asked about their experiences of living with common oral diseases and the possible causes of their oral conditions. Participants were probed further on provided responses to understand deeper their perceptions about oral diseases.

Interviewers underwent training about the appropriate use of probing, iterative questioning, and frequent debriefing to assure quality control measures. Interviews were done by 2 trained interviewers with a dental background, a master's in public health, and previous experience in qualitative data collection. Interviews were guided by developed semi-structured interview guide (refer to supplementary file) to ensure consistency and trustworthiness of the study results. The semi-structured interview guide explored the respondents' perceptions on possible causes and effect of common oral diseases they suffered from in the language they understand.

Interviewers were required to recognize their potential preconceptions and biases "ability to sustain a reflexive stance" [10]. Bracketing method was assured by discussing with fellow researchers earlier during the conceptualization of the research protocol by making notes on existing personal view-points. During data collection, daily discussions occurred to recognize and put aside the pre-conceptions and bias among researchers.

### Data management and analysis

Data from the participants were transcribed verbatim by the research team, then translated into English for analysis. The thematic analysis aimed to inductively identify the themes and sub-themes of interest in the data and use them to interpret and make sense of research data [11]. The researchers [JM, YM-K] firstly read the transcripts independently without any coding. NVivo software version 11 was used to code and organize the data. The codebook was created by each investigator; initial 'codes' were identified and assigned to a group of text'. An agreed codebook with finalized codes was used to code the rest of the transcripts. The second level of analysis included consensus by coders [JM; YM-K] on the higher level codes, sub-themes and themes arising from the codes. Five themes emerged that were categorized in two broad domains (Fig. 1). Trustworthiness was ensured through the following criteria:

### Credibility

Credibility refers to the degree to which your research can be deemed responsible and accurate. It safeguards against subjective experiences, emotions, and perspectives that may otherwise obscure the true nature of your research subject [12]. Credibility establishes whether the research findings represent reasonable information drawn from the participants' original data and is a correct interpretation of the participants' original views [12]. For our study, credibility was observed by considering 2 different researchers who independently coded, analyzed, and interpreted data on perceptions of possible causes and effect of oral diseases.

### Transferability

Refers to the degree to which the results of qualitative research can be transferred to other contexts or settings with another group of people [12]. For our study, a comprehensive and detailed description of the research setting and participants was done to be able to understand

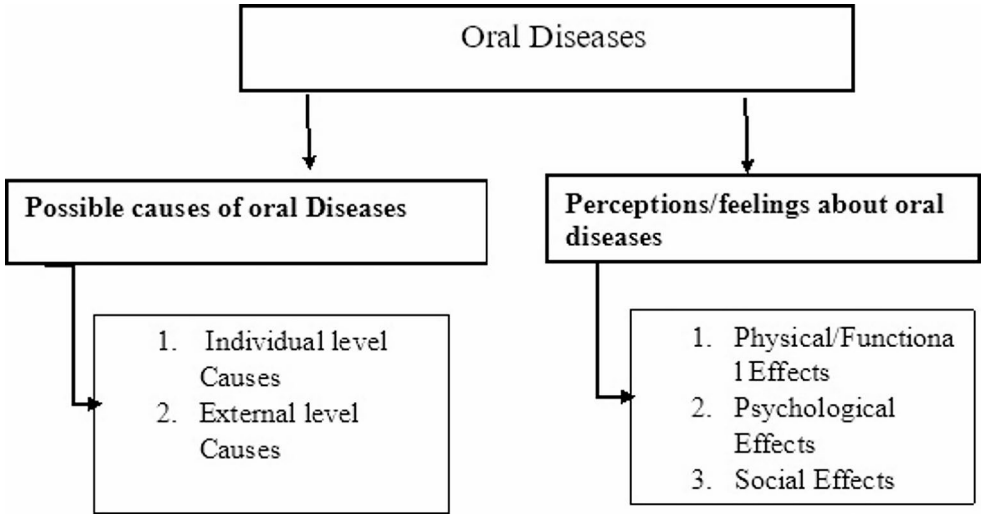



**Fig. 1** Illustration of domains and themes that emerged from the data

the context of our research. Also, the description of the data collection process was clearly detailed.

#### Dependability

The stability of findings over time. It involves in-depth methodological description to allow study to be repeated [12]. As recommended in the literature, we also provided in-depth methodological description to allow our study to be repeated.

Ethical consideration.

## Results

### Participants characteristics

Twenty-one adults, age group 18–30 years and age 31 years and above (Table 1) participated in the IDIs until no new information was retrieved.

### Themes emerged from the data

Regarding the domain on possible causes of oral diseases of common oral diseases (caries and/or periodontal diseases), two major themes emerged (individual causes and external causes).

For the second domain on perceptions about oral diseases, three themes identified were physical effect, psychological effect and social effect as represented in the Fig. 1.

### Possible causes of oral diseases

In the domain of "possible causes of oral diseases", the individual/ and external causes emerged as felt and experienced by the participants.

### Theme 1: individual level causes of oral diseases

Under this theme, respondents described various individual-related factors that they perceived as possible causes for developing their common oral diseases (caries and/or periodontal diseases). For individual causes, interviewees described their behavioral lifestyles that they thought contributed to caries and periodontal diseases development. They highlighted dietary habits, oral hygiene, delay of dental visit or check-ups and negligence among possible causes of their oral diseases. In addition, participants highlighted older age, lack of knowledge and poverty among individual causes of their oral conditions.

For diet habit, HIV-positive and HIV-negative participants highlighted consuming sugary foods.

such as biscuits, candy, sugary drinks, and syrup medication as the main risk factors for their teeth destruction.

**Table 1** Distribution of participants in the study

| Interviewees groups | 18–30 years old | 31 and above | Total = 21 |
|---|---|---|---|
| HIV-positive | 4 | 6 | 10 |
| HIV-negative | 5 | 6 | 11 |

*"It (i.e. dental caries) was caused by eating too much of biscuits and licking too much of candies" (A19 years old HIV-positive female).*
*"I used to be that person who was taking much sugar, very fond of sweet stuff and like chocolate" (A 50 years old HIV-negative female).*

In addition, respondents highlighted sweets from fruits, stones within food and food that was not well cooked among the causes of their oral disease development.

*"The fruits that we like to take, such as pineapples, figs, mangos, they are very sweet and sugary and I guess that they can also have a negative effect, so presumably they can act as the catalysts for the teeth disease" (A 42 years old HIV-negative man).*
*"According to what I think, the food that we used to take at school, can be blameworthy because I used not to have teeth diseases but as we all know, sometimes at high school the food that we eat isn't ready enough to be eaten and it has fractured all my teeth". (A 20 years' old HIV-positive female).*

Regarding oral hygiene, interviewees mentioned not cleaning teeth and the use of inappropriate tooth cleaning material as causes of their common oral diseases.

*"The teeth disease that I am living with, has been perhaps caused by the fact that I used to live my life without cleaning my teeth. I was acting very childishly, I didn't know the importance of brushing teeth regularly, especially after eating, for some reason the toothache was caused by that". (A 47 years old HIV-positive female)*
*"At my time, many people didn't have tooth brushes and toothpaste. We used teeth sticks. We used to select soft sticks which were everywhere along the path. They were also some herbs they used to tell us that they can brighten the teeth but as we grew up, we realized that those herbs also were harmful". (A 49 years old HIV-negative female)*

Participants also mentioned delay in dental health seeking as a possible cause of their oral diseases. They highlighted that they only remembered dentists when their oral needs became severe.

*"You know that here in Rwanda we don't go immediately go for treatment. A tooth can start to cause pain and you delay, thinking that it is not serious and sometimes the pain gets relieved; but when you finally go for treatment, they tell you that the cavity has already been very deep". (A 39 years old HIV-negative male).*

Respondents further reflected on their neglecting behaviors as another possible cause for their oral disease.

*"I used to be very neglectful, all I could do was to gargle water and then spit, but I couldn't a tooth brush and brush my teeth. (A 19 years old HIV-positive female).*

Interviewees mentioned older age among passible causes for their oral diseases.

*"Things they are extremely different from how they used to be during the childhood, as we keep growing up, teeth also tend to become mediocre, the gums also start to get ruined, it is very disappointing to face that misadventure, I wish we could age differently". (A 42 years old HIV-negative male).*
*"Are you kidding! We didn't know about them (meaning about tooth brush and tooth paste), we were using some thin pieces of wood, we didn't know about toothbrush or toothpaste, only thin pieces of wood and gargle with water, that's all. But astonishingly, when I started to brush my teeth they were still intact. I started to have the teeth disease in the adulthood." (A 47 years old HIV-positive female).*

Respondents also cited their poverty or financial blockage age a possible cause for their oral diseases.

*"Poverty sometimes kills, you can think: will I keep getting Colgate for teeth cleaning all the time? Where will I get that money?" (A 49 years old HIV-negative female).*
*"It was tough for me to get the money; I was broke to buy even a toothpaste; I was telling my children, who were supposed to go to school, to use only the toothbrush". (A 61 years old HIV-positive female)*

Lastly, lack of knowledge was among individual possible causes of oral diseases development as shown by answers from the interviewees.

*"Exactly, it did happen to me, I am not exaggerating, but another thing that I can say is that, the lack of enough knowledge related to how people are supposed to take care of their teeth. May have played a major role" (A 32 years old HIV-negative male).*

#### Theme 2: external causes of oral diseases

Under the second domain, the participants highlighted issues such as staying in a rural area, effect of genocide and HIV-related factors and heredity as possible causes of their oral diseases.

Respondents highlighted that living in rural area is destructive to oral health mainly due to carelessness regarding oral health and the use of traditional medicine in rural area.

*"living in a rural area also sometimes is not easy. At first I suffered from the gum and in that rural area they never used to care about that, unless may be now they might have started to be aware, the gum became swollen and slowly by slowly it removed from the teeth. They told me that it is "ifumbi" and told me that they will bring some herbs which treat that. They applied 'medicine' on the gum and they gave me others to drink, I think I might have drunk like ten liters like that. When they applied them, the following morning there was like a very big blood clot. When it didn't work, someone came and advised my parents to look for amoxicillin tablets which might be effective. They gave them to me but without taking me to the health facility. Rural area might be destructive". (A 49 years old HIV-negative female)*

When asked about the possible causes of her oral conditions, one interviewee perceived the head injury from the Rwanda genocide perpetrated against Tutsi in 1994 as a possible cause of her oral diseases.

*"It is a big problem; my teeth disease is a consequence of the genocide against Tutsis where I was wounded on the head. That is where it started from". (A 38 years old HIV-negative female).*

Different views were highlighted by HIV-positive participants regarding HIV-associated factors. Few interviewees perceived ARVs as a possible cause for their oral diseases (dental caries and periodontal diseases).

*"I started to feel that there was something wrong with my teeth, when I was taking the ARVs. I was not supporting them, my teeth would hurt right after taking them and it was an unbearable pain and the teeth felt loose." (A 50 years old HIV-positive female).*

One HIV-positive participant was unsure whether HIV-related factors were associated with their caries and / or periodontal disease development.

*"What makes me think so, is that before I got that information that there was something wrong with my blood (meaning HIV-infection), I hadn't had any problem in my mouth. During my 4th pregnancy that is when I found out. I went for the antenatal care, and I had not started to considerably suffer*

*from the teeth. I was told that I had been infected by the virus, my teeth were still fine, but what I do remember is that, during that pregnancy, my teeth were extracted but I am still not able to link one disease to another, it was vague, because I also remember that I used to feel slight tooth pain, even before the infection was discovered." (A 47 years old HIV-positive female).*

Participants of IDIs perceived heredity as one of the causes of their oral diseases development

*"I guess that some of my relatives also suffer from teeth diseases; I don't know, it might be a hereditary disease, I must say". A 24yrs old HIV- male.*

Table 2 shows patterns comparing HIV-positive and HIV-negative interviewees' responses in regard to possible causes of their oral diseases.

#### Perceptions about effect of oral diseases

HIV-positive and HIV-negative adults expressed their perceptions on having oral diseases (dental caries and periodontal diseases) through theme main themes: Physical/ functional effect, psychological effect, and social effect.

#### Theme1: physical/ functional effect

Within the physical or functional effect, interviewees expressed any physical or functional issue experienced as a result of their oral diseases. They mentioned inability to eat, inability to smile or laugh and pain.

*"They (caries) make me look as if I am toothless, I am like the famous "Manyobwa (a Rwandan lady famous in local movies known of speaking and looking funny because she lacks all her teeth) who was edentulous" (59 years old HIV-negative male).*
*"The consequence is that my cheeks keep on falling more and more, because as the teeth go out, the appearance becomes bad" (A 34 years old HIV-positive male).*

**Table 2** Patterns comparing HIV-positive and HIV-negative interviewees' responses in regard to possible causes of their oral diseases

| HIV status | Themes about possible causes of oral diseases | |
|---|---|---|
| | Indiviual causes | External causes |
| **HIV- positive** | 19* | 2* |
| **HIV- negative** | 23* | 6* |

*indicates the number of frequency interviewees indicated possible causes of oral diseases under each theme category

In addition, all participants reported difficulty in eating various kinds of food due to caries and/or periodontal diseases.

*"I am talking about meat, cassava, all those kind of things, you know, my teeth can't handle them, stuff like the sugarcane I can't really try to take" (A 28 years old HIV-negative female).*
*"I cannot chew the sugar cane, and I used to, no more eating sweetcorn, I can't take meat on a bone and so on" (A 34 years old HIV-positive male).*

Participants also expressed that they could not smile or laugh as they wanted due to caries and periodontal diseases that made their teeth unattractive.

*"You don't feel free. When you want to smile, you try to hide your teeth when you should be laughing like others do" (A 49 years old HIV-negative female).*
*"Now I hardly laugh, I don't do it like I used to when my teeth were still looking attractive" (A 34 years' old HIV-positive male).*

Furthermore, respondents experienced pain due to common oral diseases. They experienced double pain, including pain during tooth extraction and the pain (described as emotional pain) of losing their teeth.

*"It was very painful I couldn't help it, it really drove me crazy, I was unable to take anything. When something metallic touched that tooth, I felt like an electric current crossing my body" (A 19 years old HIV-negative male).*
*"So you understand how it feels, one will have to deal with double pain, the first one is that you have lost your tooth, and another one is the pain that you will get when the dentist will be taking out the rest of the tooth" (A 50 years old HIV-positive female).*

#### Theme 2: psychological effect

For this theme, IDIs interviewees reflected on psychology-related matters they faced as a result of living with oral diseases (caries and periodontal diseases). Affected appearance, annoyance with the presence of oral diseases, broken heart due to oral diseases, feeling inferior, anxious, unhappy, worry and hopeless.

Regarding appearance, all participants reported that their look or appearance was affected due to teeth or gum; they felt unattractive and had fallen cheeks resulting from tooth loss.

HIV-positive living with caries and/or periodontal diseases reported that they were annoyed by these common oral diseases.

*"It has been very annoying to see my gum getting thicker, and to suffer from the dental caries, there were always some food rests that were remaining in those cavities, leading to that severe pain." (A 34 years old HIV-positive male).*
*"I am very annoyed because my teeth are broken and leave some space between them". (A 59 years old HIV-Positive male).*

In addition, interviewees highlighted that they had a broken heart as a result of caries and/or periodontal diseases.

*"Look, I might be with people and when you laugh like the others, they might see blood all over your teeth and ask you what happened. At that time, you feel touched" (A 49 years old HIV-negative female).*
*"Teeth problems broke my heart". (A 50 years old HIV-positive female)*

Moreover, interviewees reported that they experienced feelings of inferiority and lack of pride due to caries and/or periodontal diseases.

*"To be honest, I was not proud of myself" (due to holes in the teeth). (A 24years old HIV-negative female).*
*"Since my early childhood, I couldn't stand the fact that my teeth were not as attractive as I wanted them to be, it was making me feel very inferior". (A 50 years old HIV-positive female).*

Participants also showed the feeling of anxiety related to the potential of having their teeth extracted due to oral diseases (dental caries and/or periodontal disease).

*"Well! There is always an anxiety about how it will be when the teeth will be taken out". (A 42 years old HIV-negative male)*

Furthermore, interviewees highlighted that they were unhappy due to caries and/or periodontal diseases.

*I see them (teeth) badly; I am not happy with them". (A 20 years old HIV-negative male).*
*"I can't be happy with missing teeth, and the remaining ones being carious and broken". (A 34 years old HIV-positive male)*

Some respondents were worried about losing their teeth due to caries and periodontal diseases and that common oral disease might result in oral cancers. Some HIV-positive interviewees were worried about interactions with other due to toothless.

*"There are a lot of questions that I always have on my mind, wondering how it can be if I turn toothless in case all the teeth would be taken out" (A 42 years old HIV-negative male).*
*"Nowadays the fear of oral cancer is hunting me because recently I saw a swelling in regards to this upper tooth when usually it is this lower anterior. I kept thinking that this might be oral cancer up to the time it busted. But even now I am still thinking like that" (A 49 Years old HIV-negative female).*
*"I was having that kind of feeling wondering how I will get back to mingle with others while looking toothless" (A 50 years old HIV-positive female).*

Lastly, one interviewee experienced hopelessness and wished to die due to common oral diseases (dental caries and periodontal disease).

*Sometimes I am full of sorrow because I know where my teeth problem is coming from (genocide head wound). I keep thinking about it and feel desperate, saying to myself that it would have been much better if I died instead of living with such a handicap. (A 38 years old HIV-negative female)*

**Theme 3: social effect**

For social effect, participants expressed isolation/ avoidance of social interactions, feeling ashamed and exposure to mockery as effects resulting from their oral diseases.

Respondents of IDIs reflected on self-isolation due to caries and periodontal disease effects.

*"It is not easy. Like now that I lost teeth, I cannot join peers without wearing a prosthesis. It is a problem. Another thing, you cannot tell everyone about your problem, that is also a consequence". (A 28 years old HIV-negative female.)*
*"I used to be a member of the choir but right now, I don't think that I can take a microphone and sing anymore, it's not easy". (A 50 years old HIV-positive female)*

In addition, HIV-positive and HIV-negative respondents reflected on experience of feeling shame, hiding teeth and embarrassment as a result their oral diseases (caries and periodontal disease).

*"See, you cannot even kiss your lover, in the way that you want to I can't judge people but on my side I feel very ashamed." (A 50 years old HIV-positive female).*
*"These days I am glad that I wear my face mask to hide this, but I don't know what will happen after this (meaning after COVID-19 pandemic). It (face mask) has been a solution, sometimes I tell myself*

**Table 3** Patterns comparing HIV-positive and HIV-negative interviewees' responses in regard to perceptions of oral diseases effect

| HIV status | Themes from perception of oral diseases | | |
|---|---|---|---|
| | Physical/functional effect | Psychological effect | Social effect |
| HIV-positive | 37^ | 31^ | 11^ |
| HIV-negative | 20^ | 17^ | 13^ |

^ stands for the number of frequency interviewees indicated perceptions on oral diseases under each theme category

*that God did this to help me stepping out, otherwise I wouldn't be seen in public". (A 50 years old HIV-positive female).*

Interviewees also highlighted the experience of being mocked by others due to the problem of caries and/or periodontal diseases.

*"Another area in which my teeth are hindering me is in social life where many people show a bad reaction towards me. In their conversations they can mock me and point at me, saying: look that young man, he is edentulous, he lost his teeth. All that are hindrances". (A 20 years old HIV-negative male)*

Table 3 shows Patterns comparing HIV-positive and HIV-negative interviewees' responses in regard to perceptions of oral diseases effect.

Figure 2 is a summary diagram of data visualization on perceptions and possible causes of oral diseases among study participants.

## Discussion

### Possible causes of oral diseases (caries and periodontal diseases)

This study explored perceptions about possible causes and effects of caries and/or periodontal diseases on HIV-positive and HIV-negative adults. The study is the first to consider qualitatively, the perceptions on possible causes and effect of oral diseases among HIV-positive and HIV-negative adults in Rwanda. According to the results from this qualitative study, interviewees perceived individual factors (diet habit, lack of oral hygiene, delayed dental visits, negligence, older age, heredity) and external factors

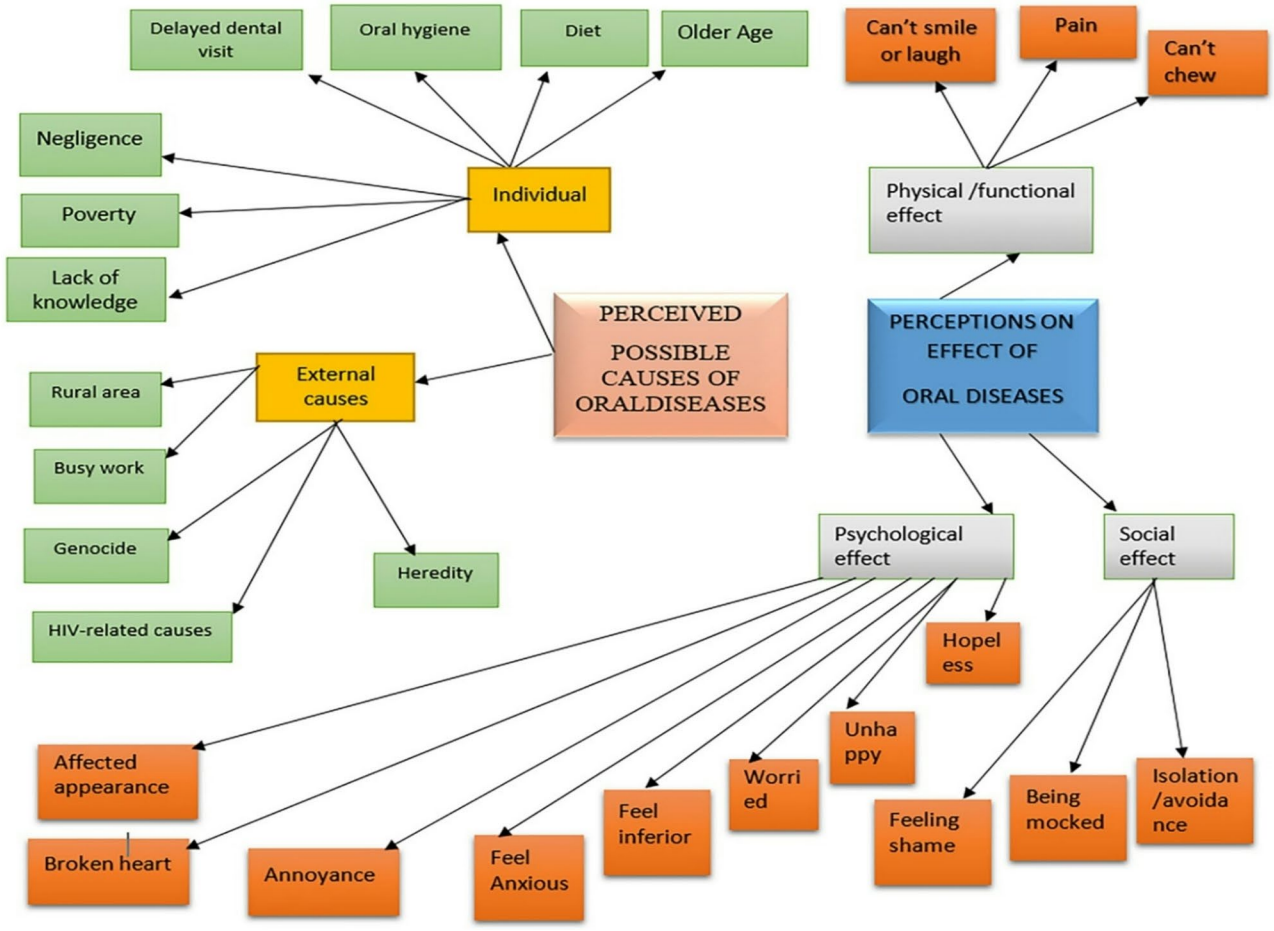



**Fig. 2** Summary diagram of data visualization on perceptions and possible causes of oral diseases among study participants

(living in rural area, HIV-infection, genocide and poverty, busy work) as possible causes for their oral diseases (dental caries and/ or periodontal diseases). In addition to the common factors, some HIV-positive participants perceived HIV-related factors (using ARVs and HIV infection) as possible causes for their oral conditions.

#### Individual possible causes for oral diseases

As per the literature, individual factors such as behaviours and lifestyle factors play a significant role in caries and periodontal development. As reported by Štefanová and colleagues, sugary diet and poor tooth brushing habits are among the main risk factors for caries developments [13]. Similarly, the behavioral factors were perceived to be associated with caries and periodontal diseases. Hall-Collin and colleagues also reported sugary diet and lack of oral hygiene among risk factors for dental caries [14]. In addition, our study findings were similar to a study by Versa and colleagues in Ethiopia, which showed relation of dental caries with a lack of toothbrushes, consumption of sugary food, and low income [15]. Same as dental caries, poor oral hygiene, poor work flexibility (busy work), and dietary factors (sugary, inadequate diet), were reported among risk factors for periodontal disease development [16].

In addition, older age and HIV-related factors arose as one of the perceived risk factors contributing to the participants' common oral diseases as reported by older interviewees aged more than 40 years. Similar results were reported by Gayatri and colleagues who found older age to be significantly associated with oral diseases. Fokam and colleagues also emphasized the role of systemic diseases (mostly those that decrease the immunity system capability) regarding common oral disease development. For example, HIV infection is reported to be a risk factor for periodontal diseases [17]. This issue is linked to immunological changes in HIV infection that may alter the patient's ability to respond appropriately to infection, including those due to sub-gingival bacteria [18].

Heredity was also highlighted among possible causes of common oral diseases for our study. The literature highlights genetics as one of the determinants of highly prevalent oral diseases, mostly dental caries, periodontal disease, and some oral cancers [19]. Various suggested genetic differences exist in caries susceptibility, especially between Africans and Caucasians [19, 20]. The literature highlighted different genes and gene-protein networks associated with protection or risk of dental caries [19, 21]. Those genes are related to enamel formation, development and mineralization, host immune response, and the composition of saliva [21]. Considering genetic factors, there is a need for contextual strategies to promote oral health, especially in African countries, including Rwanda.

#### Discussing possible external causes for oral diseases

One interviewee perceived genocide as a possible cause for caries and periodontal diseases she experienced. The respondent expressed that the head wounds she experienced during the genocide against Tutsi were the main possible cause for oral conditions (dental caries and periodontal diseases) she suffer from. These surprising results are plausible and should not be ignored because previous studies have linked traumatic head injury to dental caries and periodontal diseases [22]. This relationship can be explained by the inability to do proper oral hygiene, the post-traumatic anxiety, depression, and distress that can affect individuals' behaviors towards oral care.

Despite this arising from a single participant, this provides information on possible effects of these external factors on oral health. Rwanda had a unique experience in Africa of passing through genocide and the consequences of genocide on general health are numerous. Korman highlighted that the genocide has left scars that are not only mental but physical as well [23]. Therefore, oral health interventions should consider the uniqueness of Rwanda's context for effectiveness.

In addition, HIV-positive and HIV-negative respondents of IDIS, perceived living in rural areas as a possible cause for their oral diseases (caries and periodontal diseases). Researchers have documented similar results about disparities in distributions of caries and periodontal. People from rural areas are more affected by dental caries and/or periodontal diseases mostly due to inaccessibility to oral health services, low socio-economic status, and low education level [24–28]. Therefore, interventions specific to rural populations are essential to ensure good oral health in rural areas.

Furthermore, Using ARVs and having HIV infection were perceived as an additional cause to development of oral diseases among HIV-positive people and this was specific to this group only. This may be explained by the increased burden of common oral diseases reported among HIV positive people than the general population as reported in the literature [7, 8].

#### Perceptions of participants on effects of oral diseases

The reported perceptions of participants on effects of oral diseases among HIV-positive and HIV-negative interviewees was through physical and/or functional effects. Participants reported that their appearance, eating, smiling or laughing, were negatively affected and that they experienced pain from oral diseases.

Interviewees also highlighted psychological effects of oral diseases including heartbreak, annoyance, feeling inferior, anxiety, unhappiness, worry, hopelessness, and

unhappiness. Lastly, participants of IDIs interviews experienced social effects, including avoidance or self-isolation, embarrassment or shame and being mocked.

In line with our study, scholars have also reported the effect of having caries and periodontal diseases on physical, functional, psychological, and social lives [29]. Similar to the findings from our qualitative study, the literature highlights that dental caries and/or periodontal diseases lead to pain, suffering, psychological embarrassment, social deprivation, difficulties in eating various foods, affected well-being, and this causes individual and collective damages [30]. For example, a study by Shahzad and colleagues reported sadness, sleeplessness due to pain, shame, and difficulty living and working as consequences experienced by people affected with caries and or periodontal diseases [31].

In our study results, the summary patterns on perceptions of oral diseases showed more frequency of HIV-positive interviewees reporting physical or functional effect and psychological effects compared to HIV-negative counterparts. This finding agreed with the existing literature report where different scholars highlight that oral diseases among HIV-positive people are more severe and difficult to manage compared to oral diseases among the HIV-negative individuals [4]. This effect indicates the importance of considering oral health interventions that take into account physical, psychological, and social components especially among the high risk group of HIV-positive people.

As a limitation, this study considered the insights from interviewees only and did not considered key informants. Further, studies that involve key informants such as healthcare professionals, nurses and physicians who work in HIV service are necessary to get more insights on this topic.

## Conclusion

According to study results, HIV-positive and HIV-negative adults reported various individual level, and external level factors as possible causes for caries and periodontal diseases they were suffering from. Also, HIV-positive and HIV-negative participants experienced physical or functional, psychological, and social effects due to having oral diseases with more patterns in HIV-positive interviewees. However, in regard to HIV status, the summary patterns on perceptions of oral diseases showed more frequency of HIV-positive interviewees reporting physical or functional effect and psychological effects compared to HIV-negative counterparts. This finding agreed with the existing literature report where different scholars highlight that oral diseases among HIV-positive people are more severe and difficult to manage compared to oral diseases among the HIV-negative individuals [4]. Also, using ARVs is another issue perceived as an additional cause to development of oral diseases among HIV-positive people and which is not the case for HIV-negative counterpart. The last can also explain the increased burden of common oral diseases reported among HIV positive people than the general population [7, 8]. Therefore, oral health interventions are needed to prevent caries and periodontal diseases and promote oral health among Rwandese especially those at high-risk such as HIV-positive persons.

### Recommendations for addressing oral diseases in HIV-positive individuals in rwanda

There is a need to integrate oral healthcare to HIV services in Rwanda for addressing oral diseases in HIV-positive individuals. In addition, contextualized oral health education and oral diseases prevention interventions specific to HIV-positive people are needed in Rwanda. Moreover, oral health professionals, nurses and physicians in HIV services should receive regular training in area of HIV and oral health to engage them take actions to promote good oral health among this high risk group of HIV-positive people.

#### Abbreviations

| | |
|---|---|
| CMHS | College of Medicine and Health Sciences |
| HIV | Human Immunodeficiency Virus |
| IDIs | In-depth Interviews |
| IRB | Institutional Review Board |

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12903-025-06273-y.

Supplementary Material 1

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#### Author contributions

JM, YM-K, and VY participated in the study conception and design. JM corrected the data. JM, YM-K analyzed data. JM drafted the manuscript. JM, YM-K, VY, and AM reviewed the manuscript and supported data interpretation and discussions. All authors revised and approved the final version of the manuscript.

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#### Data availability

All data generated or analyzed during this study are included in this published article and its supplementary materials.

## Declarations

### Ethics approval and consent to participate

This study has been performed in accordance with the Declaration of Helsinki. The ethical clearances to conduct the study were received from the Human Research Ethics Committee (No M200351) from the University of Witwatersrand, the Institutional Review Board (No 573/CMHSIRB/2019) from the University of Rwanda, and the Research Ethics Committee of Kigali Teaching Hospital (No EC/CHUK/026/2020). Informed written consent was given to all participants before data collection. To obtain informed consent, we first provided adequate information to participants through an information sheet that explained in detail the nature and processes involved in the study, the reason for the study, and the intended outcomes. We allowed participants to ask questions and respond to each question. We ensured participants comprehended the provided information. Then, participants who agreed to participate in our study voluntarily signed the consent form. The confidentiality of patients was observed by using an anonymous questionnaire. The signed commitment letter to support any HIV-positive interview who could show discomfort during IDIs was obtained from Psychology department before starting our data collection.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

### Author details

[1]Department of Preventive and Community Dentistry, University of Rwanda, Kigali, Rwanda
[2]Department of Community Dentistry, University of Witwatersrand, Johannesburg, South Africa
[3]Department of Pediatrics and Child Health, University of Rwanda, Kigali, Rwanda
[4]Department of Community Dentistry, University of Western Cape, Cape Town, Bellville, South Africa

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