Use of dental care services among adolescents living with HIV on ART in Kampala, Uganda: a crosssectional study

Maria Gorreti Nakyonyi



Centre for International Health Faculty of Medicine University of Bergen, Norway 2021/23

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Abstract

Background: As of 2020, the United Nations International Children's Emergency Fund (UNICEF) reported the incident HIV cases among adolescents (10-19 years) globally to be 150,000 out of which 400,010 were new infections among young people. One hundred and fifty thousand people out of the 1.2 million living with HIV in Uganda are under the age of 15. Oral problems can significantly compromise the general health and quality of life of individuals living with HIV, yet many of them do not receive the dental care services they need. Despite high vulnerability for oral disease in persons with HIV, many still do not use dental care services regularly.

Objective: The purpose of this study was to assess the prevalence and determinants of ever-use of dental care services among the adolescents living with HIV on ART, between 10-18 years of age, attending selected HIV clinics in Kampala, Uganda.

Methods: A cross-sectional study was carried out between March and September 2020. The study purposively recruited 202 adolescents between 10 to 18 years selected from 4 specific HIV clinics in Kampala: Mulago Immune Suppressive Syndrome (ISS) clinic, Kawaala Health Centre IV, Kisenyi Health Centre IV, and Kiswa Health Centre III. Data was collected through telephone interviews using questionnaires uploaded on android phones. Andersen's behavioural model guided the selection of variables in terms of ever-use of dental care services as the outcome- and predisposing, enabling, need related factors, and personal oral hygiene and dental practices as exposure variables. Data was analysed using Fischer's exact test for cross-tabulation and modified Poisson regression for multivariate analysis.

Results: The overall study sample constituted 202 adolescents, majority of which were males, (55.9%). The median and mean age of the participants were 13- and 13.6 years, respectively with 52.0% (105/202) aged between 10-13. The prevalence of ever-use of dental care services among the participants was 12.4%. A total of 90.1% of the participants were not afraid of going to the dentist. Age and gender did not associate with ever-use of dental care services. A modified Poisson regression revealed a positive association of failure to get dental treatment because it was not part of the medical appointment with ever-use of dental care services with a prevalence ratio (PR) of 3.16 95% confidence interval (CI) 2.41-4.16). Fear of going to the dentist was found to be positively associated with ever-use of dental care services with a PR of 2.62 and CI of (1.04 - 6.60). Regarding the need related factors, those who perceived health of teeth and mouth as fair were less likely to have ever-used dental care services with PR of 0.22 and CI of (0.05-0.98). Among age group 14-18, 100% of participants that confirmed long queues at the dental facilities reported ever-use of dental care services.

Conclusion: The study revealed that the frequency of ever-use of dental care services was low among the adolescents living with HIV in Kampala, Uganda. Factors associated with ever-use of **2** | P a g e

dental care services according to enabling factors included fear of going to the dentist, failure to get dental treatment because it was not part of the medical appointment. Among need related factors associated with ever-use of dental care services was perceived health of teeth and mouth. None of the predisposing factors and personal oral hygiene and dental practices showed an association with everuse of dental care services among the study group.

Key words: Use of dental care services, HIV, ART, adolescents, Kampala, Uganda

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Acronyms and abbreviations

AIDS	Acquired Immunodeficiency Syndrome		
ART	Antiretroviral treatment		
DMFT/dmft	Decayed, missing, filled teeth		
EASR	Eastern and Southern African Region		
GF	Global Fund		
HAART	Highly Active Antiretroviral Treatment		
HCSUS	HIV Cost and Services Utilization Study		
HIV	Human Immunodeficiency Virus		
KCCA	Kampala Capital City Authority		
MJAP	Makerere University Joint AIDS Program		
NUG	Necrotizing Ulcerative Gingivitis		
NUP	Necrotizing Ulcerative Periodontitis		
PEPFAR	President's Emergency Plan for AIDS in Africa		
PLHIV	People Living with HIV		
SD	Standard deviation		
UPHIA	The Uganda Population-Based HIV Impact Survey		
UNAIDS	Joint United Nations Program on HIV and AIDS		
US	United States		
IRR	Incidence Rate Ratio		
PR	Prevalence Ratio		
CI	Confidence Interval		
MakSHSREC	Makerere University Institutional Review Board, School of Health		
Sciences Research and Ethics	s Committee		
UNCST	Uganda National Council of Science and Technology		
REK	Norwegian Regional Ethics Committee		
FDI	World Dental Federation		
SDGs	Sustainable Development Goals		

Supervisors and Acknowledgements

Main Supervisor:

Professor Anne Nordrehaug Åstrøm, DDS, DPH, PhD Department of Clinical Dentistry, University of Bergen, Norway

Co Supervisors:

Dr Catherine Lutalo Mwesigwa, BDS, MSc, MDP&PH College of Health Sciences, Makerere University, Uganda Dr Nancy Birungi, BDS, PhD, Oral Health Centre of Expertise in Western Norway Ms Grace Nabaggala Ssanyu, BBLT, MSc (CEB), Clinical Epidemiology Unit, Makerere University, Uganda

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Dr Isaac Okullo, DDS, PhD College of Health Sciences, Makerere University, Uganda

1.0 Background

1.1 Literature review

1.1.1 Global Burden of HIV in the adolescent population

The presence of Human Immunodeficiency Virus (HIV) causes Acquired Immune Deficiency Syndrome (AIDS) [1]. Acquired Immune Deficiency Syndrome is one of the main causes of death among young people (aged 10-24) in sub- Saharan Africa and globally [1, 2]. In 2019, it was reported by the Joint United Nations Program of HIV and AIDS (UNAIDS) that of every seven incident HIV infections, two were among the young people (15-24 years) [2]. As of 2020, there is an increase in the number of adolescents newly infected with HIV as reported by the United Nations International Children's Emergency Fund (UNICEF). Of the 400,010 HIV estimated incidence cases among the young people aged 10 to 24 years in the same year, 150,000 of these were adolescents aged 10-19 years. [3]. Adolescents and young people are still heavily affected by HIV, accounting for 34% of all new infections in 2019 [2]. In the Eastern and Southern African Region (ESAR), the greatest number of new infections occur among adolescents and young adults [4]. With approximately 54% of people living with HIV in ESAR, this region remains the most afflicted [5]. The Eastern and Southern African region has over 60% of adolescents and children living with HIV [6]. As of 2018, the numbers of adolescents and children living with HIV was approximately 1.8 million. Within the same year, the estimated incidence cases between 15-24 years in the same region (ESAR) was 290,000 [6]. It is estimated that by 2030, that there will be 3.5 million incident cases of HIV in the adolescent population [7]. Despite efforts to combat HIV in ESAR, there is still a high prevalence of HIV in the adolescent population as most children that were born with HIV are currently crossing over into adolescence [3]. This could be because of increase in accessibility and availability of Antiretroviral treatment [1].

1.1.2 HIV and Antiretroviral status in Uganda

The Uganda Population-Based HIV Impact Survey (UPHIA) of 2016 indicated that the current prevalence of HIV among adults aged 15 – 49 years in Uganda is 6%, 0.5% in children under the age of five, while among those aged 5 – 14 years, it is 0.5% [8]. By 2020, there were approximately 6,119 new HIV infections in the Uganda adolescent population aged 10-19 [9]. In addition to the same report, over 100,000 of adolescents in Uganda were living with HIV in the same year [9]. Wakiso and Kampala districts had the highest burden of HIV in Uganda [9]. In 2016/17, 200,787 patients in Uganda were enrolled on antiretroviral treatment (ART) with 53,987 enrolled on ART based on CD4 count. By June 2017 1,028,909 people were on ART, 96.1% of these are on first line

regimen and 6.3% being children under 15 years; 3.7% are on second line while 0.03% on third line [8]. By 2021, the total number of people reported active on ART had increased to 1,312,974 with 13% of these are receiving HIV care and ART services in Kampala [10]. According to the HIV Investment framework for Uganda 2021-30, 66,203 out of 102,296 children between 0 and 14, living with HIV are currently on ART. In reference to the same report, of the persons living with HIV above 15 years, 1,157,310 of 1,359, 074 were on ART as of 2019 [9]. According to preliminary results released on February 2022 from the UPHIA, there's a slight decline in prevalence of HIV from 6% as of 2016 to 5.5% among the Ugandan adult population and 1.8% among those aged between 15-24 years [11]. In Uganda, common first line ART given include either a combination of zidovudine/lamivunide plus efavirenz (nevirapine) or stavudine/lamivudine and neviparine. The second line regimen includes either a combination of stavudine/didanosine or zidovudine/lamivudine with lopinavir and ritonavir boost [12].

1.1.3 HIV and effects on oral health

Globally, HIV infection and AIDS were first identified as an epidemic in the early eighties and since then, oral health signs and symptoms have been used as an integral part of HIV screening. The spectrum of HIV-associated opportunistic diseases first present in the oral cavity hence propelling dental health care providers to the leading edge of patient care [13]. Over 90% of individuals living with HIV will have at least one oral manifestation attributed to HIV opportunistic infection in the course of life [14].

The most common oral manifestations include pseudomembranous candidiasis, angular cheilitis, necrotizing ulcerative gingivitis (NUG) and necrotizing ulcerative periodontitis (NUP) oral hairy leukoplakia, Kaposi sarcoma, human papilloma virus oral warts and common ulcerative conditions [15, 16]. Oral diseases may also cause symptoms such as dental pain, discomfort, altered taste, bleeding and swollen gums, bad oral odour and a burning sensation [17]. Additionally, oral symptoms may interfere with the daily functions of life such as chewing of food, pronunciation of certain words and sounds, disturbed sleep, and smiling and socializing with confidence [17]. In addition, several studies have shown that dental caries is associated with compromised nutritional outcomes and this is could be debilitating for the already burdened individuals living with HIV [18]. The poor nutrition eventually compromises the general well-being of these patients such as contributing to opportunistic infections, preventing proper swallowing of prescribed antiretroviral medications, and impairing the ability to speak clearly [19].

The overall health and well-being of individuals living with HIV can seriously be harmed by oral health issues. Unfortunately, many of them lack access to the dental care services they require [20]. Unmet need for dental care is defined as presence of oral health issues that have not been addressed or failure to receive routine preventive care [21]. Unmet need for health care could also be defined as the gap between services actually received versus those services graded necessary to address health issues adequately including dental care [22]. This means that it may be conceived as the subjective perception of not having obtained appropriate health care services. According to the first nationally representative study of adults living with HIV receiving care in the United States; the HIV Cost and Services Utilization Study (HCSUS), dental care is one of the greatest unmet health care needs among individuals living with HIV [21]. Given that the incidence and severity of dental disease in individuals living with HIV is greater than in the general population, available and accessible oral health care is especially important in this population [13].

A study done in Uganda, reported a caries prevalence of 84% in adults living with HIV compared to 67% and 32% in the general adult and children's populations respectively [23, 24].

1.1.4 HIV and unmet need of dental care

Challenges related to unmet need to dental care have been associated with people living with HIV [20]. In a study done among 213 black women living with HIV less than 45 years of age in Northern California, 43% had not been to a dentist and among these, 78% reported failure to receive dental care when they needed it [25]. The HCSUS investigators in the United States (US) found that 19% of 230,000 individuals living with HIV in medical care perceived an unmet need for dental care in the preceding 6 months [26]. In the baseline study of the HCSUS, it was reported that unmet dental care needs were more than twice as prevalent as unmet medical care needs. Thirty-nine thousand out of 230,900 people in the US with HIV had unmet dental care needs compared to 14,300 that had unmet medical care needs [21]. Another US study showed that the majority (52.4%) of the 2,469 HIV patients in care had not received dental care services in more than 2 years. Since receiving the HIV diagnosis,48.2% of those surveyed in the above-mentioned study reported an unmet need of dental care services and 63.2% reported their oral health as "fair" or "poor." [27]. Disparities in receipt of dental care services among individuals living with HIV have been linked to social and economic factors. In the HCSUS study, factors associated with a perceived unmet need for dental services in the past 6 months included low income, lack of insurance, low level of education, and Medicaid insurance that did not include dental benefits [26]. In a study done in North Carolina, blacks living with HIV were significantly more likely to have mobile teeth, need tooth extractions, and be irregular dental care service users compared to their white counterparts. The main obstacles to use of dental

care services included fear, high costs of dental treatment, lack of motivation at 19%, 30% and 13% respectively. The unmet need of dental care services was substantially correlated with fear, cost of dental services, racial background. In this study it was reported that 65% of participants had an unmet need of dental care services in the last 3 years [28]. Another US study carried out among 2,469 adults living with HIV re-echoed that the main hindrances to use of dental care services following an HIV diagnosis included access to dental care services, anxiety related with dental treatment and cost of dental services [29]. In the above-mentioned study, there was a positive correlation between unmet need of dental care and duration following HIV diagnosis [29]. Other common barriers to dental care use cited by individuals living with HIV include: transportation issues, the inability to find a dentist, fear of contracting an illness at the dental provider's office due to compromised immune status, fear of transmitting the virus to a provider, fear of discrimination and stigma, concerns that providers would not be knowledgeable regarding the specific needs of individuals living with HIV, and loss of confidentiality about HIV serostatus [30].

A qualitative study from the US focusing adults living with HIV above 18 years identified barriers to dental care services as; time consuming administrative procedures, long queues at the dental facilities, psychological and transportation concerns, negative attitude of the dentists towards treating them and dental phobia. The factors that favoured use of dental care services identified were access to dental insurance, support from a social worker and receiving acceptance [20]. Margaret Pereyra et al found that the odds of having seen a dentist among individuals in South Florida living with HIV were greater for participants who had a stable housing, those who had received at least high school education and more, and who had received assistance in getting dental care services [31]. Moreover, in comparison to Hispanics and non-Hispanics, participants of black origin were less likely to have visited a dentist in the two years prior. It was also noted that even though low-income persons living with HIV had access to dental care services, the rate of utilization of these services remained low [31]. A South African study involving 63 children living with HIV below 12 years on ART revealed a frequency of dental caries of 79% and unmet need of dental treatment of 90.4%. In this study, unmet need of dental treatment was defined as children examined and found with decayed, missing, filled teeth (dmft) index above zero and had not received dental care services [32]. About 60% of the children had never been to the dentist since birth, and 20% who had visited the dentist in the previous year had presented in need of emergency care [32]. A study carried out in Kenya among caregivers of children with HIV/AIDS attending HIV care clinics indicated that barriers compromising use of oral health care included; a perception of high cost of dental services, inadequate understanding and knowledge on oral health and illness management, social hierarchal roles in the decision making process, lack of social health insurance, remote service locations, unavailability of dentists, health

professionals' attitudes and prolonged waiting times [33]. In this same study, 71% of these children had never had a visit to the dentist [33].

In a Ugandan study about 17% of the 237 children with HIV investigated had been to a dentist since birth, mostly for emergency dental care services [34]. In addition, 73% of the children had at least one oral lesion, and among them, 19% reported discomfort when performing oral functions. The mentioned study also found that cervical lymphadenopathy (60.8%), oral candidiasis (28.3%) and gingivitis (19.0%) were the commonest soft tissue oral lesions. From this same study, the prevalence of soft tissue oral lesions was significantly lower in children taking HAART versus those not on HAART. The frequency of dental caries in the deciduous dentition was 42.2% while that in permanent dentition 11.0% [34].

1.1.5 ART and effects on oral health

Following the advent of Highly Active Antiretroviral Treatment (HAART) there has been a reported decrease in the prevalence of HIV-related oral lesions of 10–50% [35]. Highly Active Antiretroviral Treatment is the former terminology used to describe the combination of drug therapies in the 1990s. The term is used less today because the modern available drugs are not only highly active but offer almost a normal life expectancy to all infected individuals and it is common nowadays to use Antiretroviral Treatment (ART)in the current literature [36]. This, however, does not rule out the timely need of oral health care among this category of patients. The use of HAART has also probably changed the implications of HIV infection for oral health such as oral health related quality of life and the need for use of dental services. However, there have been few studies emanating from low-income countries, about the patterns of oral health care use in persons living with HIV after the widespread use of ART [23].

Scully et al, have reported undesirable effects of ART on oral health [37]. Antiretroviral drugs have been reported to have side effects like xerostomia, oral lichen lesions, erythema multiform from drugs like Didanosine and Zidovudine [37]. Indinavir has had reports of causing angular cheilitis [37]. Xerostomia is known for increasing the risk of dental caries and hence people living with HIV remain burdened with oral health concerns [38]. Previous studies in Uganda among adults living with HIV and taking ART have revealed a DMFT score of 4 and a need of dental care services of 96% [38]. Another study carried out among adults living with HIV taking ART in Uganda reported a DMFT of greater than 5, with a possible association between duration of ART and increased risk and severity of dental caries [23]. The above-mentioned study showed that people who had a longer duration on ART had an increased risk of dental caries [23].

No previous study in Uganda has yet identified the lifetime prevalence of use of dental care services and its determinants in the HIV adolescent population taking ART. Hence the need to find out those factors in our study to improve dental care seeking behaviour among this young group.

1.2 Theoretical framework

The Andersen model (Figure 1), is a health care utilization model developed by Andersen [39]. The Andersen model was originally developed to understand the social, individual and system factors that influence health service use. The model suggests that there are some individuals who are more likely to use health services than others and that this can be explained by a number of contextual factors: (i) predisposing; factors that existed prior to illness onset (e.g. social class which could be assessed on having assets like a mobile phone, car, motorbike, television set, etc or education level), (ii) enabling; the availability and accessibility of resources (e.g. cost of care, availability of /type of health insurance) and (iii) need; both perceived and objective as evaluated by a clinician. Thus, whilst there may be some individuals who are more predisposed to seek care, there must be the means, that is, the enabling resources for them to do so. Where predisposing and enabling conditions are present, service use will nevertheless only occur if the individual perceives there to be a need for treatment or they have been evaluated as needing treatment by a clinician. The interrelationship between these three categories of contextual factors will, in turn, determine the likelihood of personal health practices (e.g. frequency of tooth brushing) and use of services (e.g. dental attendance, attendance orientation) [40]. In the revised model, Andersen [39] suggests that health practices and service use will also influence health outcomes (both perceived and clinically evaluated health status) and satisfaction with care. Majority of studies using Andersen's model have examined individual components (e.g. *predisposing* factors) and their relationship with oral health [40].



Figure 1:Illustration of Andersen's modified behavioural model

Sourced from Andersen 1995 and Ramraj 2012

1.2.1 Andersen's Behavioral model across studies

Andersen's behavioural model has been used in several studies including one done among university students in Southern Columbia assessing barriers of access to oral health care. Results included "bad health state" as an enabling factor with students that were not satisfied with their teeth appearance less likely to seek oral health care services [41]. Another study that used the Andersen's behavioural model was a prospective study of ageing people in Norway and Sweden reporting on the association of dental care utilization with oral impacts on daily performances. The different determinants assessed in this study included social economic status based on marital status, country of origin and level of education, self-reported oral status, dentition status. Oral impacts on daily performances were assessed in effect on sleeping, eating, smiling, speaking, cleaning, emotion, and work [42]. In the context of dental care use among the elderly in Lithuania, aged between 65 and 74 years, variables considered under predisposing factors included age, gender, nationality, and education. Location of residence whether rural or urban was the enabling factor, need related factors included oral health status, oral pain, dry mouth, and missing teeth. Personal health practices included use of alcohol, smoking habits and frequency of tooth-brushing, other factors were perceived stress, and overall health. The outcome variable in this study was the dental care use during the previous year. The study reported that oral pain had the strongest association with visiting the dentist among this group of patients. Other variables that influenced use of dental care services included higher level of education and lower number of missing teeth [43]. Similar studies regarding use of dental care services among children in Saudi Arabia reported 26% of the 1397 children had never been to the dentist before. The main reasons for a past dental visit was mainly toothache and dental caries.

Perceived barriers to use dental care services assessed included financial constraints, oral health illiteracy, transportation concerns, and fear. Predisposing factors which included gender, level of parent education and nationality and need for dental care services explained use of dental care services among the younger children less than 9 years [44].

A national study carried out in Brazil assessing indicators for dental appointment scheduling in primary health care among 85,231 patients and 22,475 oral health teams categorized independent variables into individual and contextual. Individual factors included age, gender, education, marital status, ethnicity, number of residents in the household, family income while contextual variables mainly incorporated role and performance of the Oral health teams. The study utilized Andersen's model for understanding the various dimensions in dental care access. The dependent variable was seeking dental appointments at the primary health care unit in the previous year. Results of the study showed that 58.1% of participants sought dental care services at the primary health care level. Patients aged up to 42 were more likely to seek dental care services at individual level while at contextual level, oral health teams that assisted a single-family health team [45].

Another study done in China was conducted among mothers of infants between 11-14 months assessing willingness to attend the first dental visit within the first year of life. Application of Andersen's behavioural model involved demographics, maternal education, oral health knowledge, perceived severity and susceptibility to caries, perceived barriers and benefits of dental visit all covered under predisposing factors. Enabling factors involved household income, social support from family, and distance to the nearby dental facility while need related factors involved perceived oral health status of the infants. Of the 658 infants, only 30% reported their willingness to have the first dental visit in the preceding 3 months, there was negative association of perception of oral health state of infants and willingness to have the first dental visit while family social support was positively associated [46].

Andersen's behavioural model has also been used in studies in Africa, one of the studies was that of use of dental health care services in the context of HIV-epidemic among dental patients in Sudan [47]. The study was aimed at finding out if HIV awareness, knowledge and contagion risk affected utilization of dental care services among dental patients. The study involved 1260 dental patients between 20-60 years from two different health facilities. The components of Andersen's behavioural model included under predisposing factors included age, hospital, gender, and education level. Enabling factors involved HIV knowledge, risk, and previous experience with HIV. Need related factors included DMFT, perceived general and oral health. The study reported the prevalence of use

of dental care services was 53.9% in the previous 2 years. Dental patients with higher knowledge on HIV and had a past experience with HIV were less likely to visit the dentist while those who had dental caries were more likely to visit the dentist [47]. In Nigeria, a total of 400 adults between 18 and 80 years were surveyed in a study assessing use of dental care services according to predisposing, enabling and need related factors. In this study 60.8% had never-used dental health care services. Also, this study participants above 56 years, unskilled laborers, and artisans less used dental care. Under need related factors, urban dwelling was negatively associated with non-use of dental services [48]. Another study done among adult city dwellers in Burkina Faso above 15 years assessed use of oral health care services using the Andersen's model. In this study, predisposing characteristics were categorized as modifiable and non-modifiable. The modifiable factors included education, marital status, importance of oral health status and importance of brushing. Nonmodifiable factors included age and gender. Enabling factors included income level, size of family, urban setting and need related factors mainly included individual assessment of their oral health status condition. Of the 3030 adults in this study, 28% had experienced an oral health problem in the past year and 62% reported disruption of quality of life due to oral health issues. Only 28% had utilized dental care services [49]. One of the models used in a study in South Africa in assessment of dental care use among postnatal mothers was Andersen's. In this study, variables were categorized as socio-demographic, socio-economic, access and utilization factors. Access factors included travelling cost, means of transport and affordability. Factors related to use of dental care services included dental issues and past dental visits. The study involved 107 postnatal mothers who were users of dental care services and 107 controls who were not users of dental care services. Sixty- four percent of the controls had dental problems compared to the cases that had 36% dental problems. Fifty-one percent of the controls had prior dental visits compared to 64% of the cases. Participants who took less time (30 minutes) to visit the dentist were more likely to use dental care services than those who took more than an hour [50].

A systematic review assessing factors associated with dental service use using Andersen's model found that under predisposing-, enabling- and need related factors such as higher age, higher income and more health problems positively influenced use of dental care in most studies carried out among the children and adolescent populations [51]. The systematic review findings were inconsistent with adult populations, where some studies reported a positive relationship of age, gender, education, income, and oral health problems with use of dental care while others reported either no relationship or a negative relationship [51]. Other systematic reviews of longitudinal studies using Andersen's behavioural model to identify determinants of healthcare use found associations of increased heath care needs with more use of health care services [52].

High- Income &	Predisposing factors	Enabling factors	Need related factors	Outcome
Upper middle				
countries				
Southern Columbia [41]	Age	Health state	Physical pain	Oral health care access
	Gender	Dental health state	Functional limitation	
	Marital status	Mental health	Physical impairment	
	Ethnicity	Existing dental problems	Social impairment	
	Study programs	Socioeconomic status	Psychological impairment	
	Working status	Teeth appearance satisfaction	Disability	
Norway & Sweden [42]	Social economic status	Dental service type	Oral health impacts on eating, smiling,	Oral Impacts on Daily Performance
			sleeping, speaking, cleaning, social events,	
			and work	
	Gender	Satisfaction with service offered	Tooth loss	
	Marital status	Previous dental experience		
	Country of origin	Cost avoidance		
	Dentition status			
	Self-reported oral status			
	preservation of teeth			
	Satisfaction with teeth			
	appearance and oral health			
Lithuania [43]		Location of residence: rural	Oral health status	Dental care utilization in the past year
Extructing [43]	nge	versus urban	oral nearth status	Dental care utilization in the past year
	Nationality	versus urban	Oral nain	
	Level of education		Dry mouth	
	Gender		Personal health practices	
			Perceived stress	
			Self-reported systemic diseases and	
			medications	
			missing teeth	
Saudi Arabia [44]	Gender	Medical insurance		Access to dental care services in a lifetime
	Parent level of education	Type of school funding		
	Nationality	Amount of monthly income in		
		the family		
		Financial support from		
		government		
	Age			
China [46]	Level of maternal education	Family income		The will to attend the first dental visit
				within the first year of life
	Gender	Family social support	Perceived oral health status of infants	-
	Order of birth			
	Oral health knowledge	Distance from the health facility		
	Perceived risk and severity of			
	caries			
	Hindrances and uses of			
	dental visits			

Table A. 1: Summary table illustrating predisposing, enabling and need related factors as

defined across studies in high-income countries

Middle &Low-Income	Predisposing factors	Enabling factors	Need related factors	Outcome
countries				
Brazil [45]	Age	Role and importance of oral		Seeking a dental appointment at
		health teams		the Primary Health Care Unit in
				the previous year
	Gender			
	Ethnicity			
	Level of education			
	Marital status			
	Number of residents in the			
	household			
	Family income			
Sudan [47]	Age	Information concerning HIV	Perceived general health	Utilization of dental services in
			status	the previous 2 years
	Gender	Knowledge on HIV risk and	Overall health of teeth and	
		transmission	mouth	
	Type of hospital attended	Experience with HIV		
	Education level	Attitude towards HIV and dental		
		clinics		
	Travelling inside or outside Sudan	Perception on the risk of		
		contraction		
Nigeria [48]	Profession	Urban or rural dwelling	Perceived oral health state	Utilization of dental care services
	Age	Income earned	Dental issues in the previous	
			year	
	Gender		Previous dental treatment	
			received	
Burkina Faso [49]	Education	Income level	Dental issues	Utilization of oral health services
	Marital status	Family size	Prior dental visits	Experience of an oral health issue
				in the previous year
	Age	I ime at the dentist	Assessment of self-health	Practice of self-medication
	Conton	Transment to the feetlite	status	
	Gender	I ransport to the facility	Compromised quality of life	
	Policious donomination	Affordability	Compromised quanty of me	
	Hengious denomination	Cost		
	Life experience in the urban setting	Cost		
	Importance of brushing	Oral health satisfaction		
	Importance of oral health status	Life experience in the urban		
	importance of oral nearth status	setting		
	Oral health diseases and pain	Joung		
	oral nearth diseases and pain			
South Africa [50]	Age	Place of residence	Oral health problems: past	Utilization of dental care services
bount miler [50]			and present	
	Gender	Occupation status		
	Marital status	Transportation fees	Types of oral health	
			problems	
	Level of education	Income level		
	Number of children	Transportation time		
	Size of family	Means of transportation		
		Affordability and accessibility of		
		dental services		
		Knowledge of dental problems		
		and cost of services		

Table A. 2: Summary table illustrating predisposing, enabling and need related factorsas defined across studies in low and middle-income countries

1.3 Justification for the present study

People living with HIV (PLHIV) are now living longer due to ART, which means that oral diseases, such as dental caries and other oral manifestations are increasingly important to manage in this population. In addition, oral health problems of individuals with HIV like periodontal diseases are often more severe and difficult to treat than those of the general uninfected population. This is because of an already established compromised immune system, overwhelming opportunistic infections and inability of the body to combat infection [53]. Therefore, there is a need for people living with HIV to have easy access to dental care. A large fraction of Ugandans living with HIV are under 15 years of age as stated earlier [9]. It can also not be ignored that the core resource of a country's future is in the youth and yet unfortunately they are highly affected groups with HIV [3]. Nevertheless, adolescents undergo various changes at the intellectual, developmental, and structural levels that once modified in terms of oral health promotion will be pivotal in an improved quality adult life [54]. Previous studies of oral health in PLHIV conducted in Uganda have focused on the oral health related quality of life and oral manifestations in these patients [34, 55-58]. No known previous study has identified determinants pertaining to ever-use of dental health care services among adolescents living with HIV. Comparable studies conducted in South Florida targeted barriers and facilitators of access to dental treatment in adults living with HIV but did not include adolescents. Moreover, the US presents a different setting from the Ugandan context [20]. Oral care need accounts for the most unmet need in HIV positive individuals [21]. This makes it prudent to understand bottlenecks in accessing dental care services, to provide a basis for oral health policy adjustments and hence improve quality of life for the affected population. In addition, this study is essential in fulfilment of Sustainable Development Goals (SDGs) three and ten [59]. These are aimed at promotion of health, well-being of all individuals and reduce inequalities among different groups of people including those living with HIV [59].

2.0 Overall purpose of the study

Focusing 10–18-year-old adolescents taking ART and attending selected HIV clinics in Kampala, Uganda, this study aimed to assess the prevalence and determinants of ever-use of dental care services using Andersen's behavioural model.

2.1 General objective

Focusing on adolescents, 10-18 years, living with HIV and taking ART, this study set out to: - assess the prevalence of ever-use of dental care services and its association with predisposing, enabling, need related factors, personal oral hygiene and dental practices as defined by Andersen's model of health behaviour

2.2 Specific objectives

- To assess the lifetime prevalence of ever-use of dental care services among adolescents living with HIV on ART, 10-18 years old attending selected HIV clinics in Kampala, Uganda
- 2. To assess ever-use of dental care services according to predisposing, enabling, need related factors, personal oral hygiene and dental practices among adolescents living with HIV on ART, 10-18 years attending selected HIV clinics in Kampala, Uganda
- To assess the relative importance of predisposing, enabling and need related determinants of ever-use of dental care services among adolescents living with HIV on ART, 10-18 years old attending selected HIV clinics in Kampala, Uganda
- 4. To identify enabling factors, specifically adapted for the younger age group 10-13 years that are associated with ever-use of dental care services among adolescents living with HIV on ART, attending selected HIV clinics in Kampala, Uganda
- 5. To identify enabling factors, specifically adapted for older adolescents 14-18 years that are associated with ever-use of dental care services among adolescents living with HIV on ART, attending selected HIV clinics in Kampala, Uganda
- To describe oral health and related characteristics among adolescents living with HIV on ART, that had ever visited the dentist, attending selected HIV clinics in Kampala, Uganda

3.0 Methods

3.1 Study design

The present study has a cross-sectional design and was carried out between March and September 2020.

3.2 Study setting

This study was a sub-study of a larger study (here by called parent study) entitled "Oral health quality of life and dental treatment needs among HIV+ children and adolescents on ART attending selected HIV clinics in Kampala."

Kampala is the capital and the biggest city of Uganda located in the north of the largest lake in East Africa, Lake Victoria [60]. Kampala has 1,497 health facilities with only 57 offering ART services [10]. Of these, only six health facilities offering ART are directly managed by the Kampala Capital City Authority (KCCA) [7] (shown in figure 2). The KCCA is a legal entity that governs Kampala on behalf of the central government [61].

Due to limited financial resources, the parent study only obtained participants from five HIV clinics. The five HIV clinics included in the parent study were Mulago Immune Suppressive Syndrome (ISS) clinic, Kawaala Health Centre IV, Kisenyi Health Centre IV, Kiswa Health Centre III and Nsambya homecare. All the clinics were public health care facilities under Kampala Capital City Authority (KCCA) and Ministry of Health except Nsambya homecare that was a private-not-for-profit clinic.

For this sub-study, the participants were selected from four out of the five HIV clinics in Kampala included in the parent study: Mulago Immune Suppressive Syndrome (ISS) clinic, Kawaala Health Centre IV, Kisenyi Health Centre IV, and Kiswa Health Centre III. The fifth private not for profit health Centre, Nsambya homecare, was excluded because it was a private-not-for-profit health facility, and thus different from the other four clinics that were public facilities.

3.2.1. Mulago Immune Suppressive Syndrome (ISS) Clinic

Mulago ISS clinic is a known HIV clinic in Uganda under Makerere University Joint AIDS Program (MJAP) located in Mulago hospital, which is Uganda's national referral hospital in Kampala, the capital city of Uganda. Makerere University Joint AIDS Program is an organisation under Makerere University College of Health Sciences aimed at provision of services in prevention and care of patients suffering from HIV/AIDS and Tuberculosis (TB) [62]. Mulago ISS clinic is an outpatient public health care facility providing HIV care to above 315 HIV infected children and adolescents as of October 2017 located 3.5 km North of Kampala City Centre. It attends to an average of 5 new HIV ART naïve patients daily [63].

3.2.2 Kawaala Health Centre IV

Kawaala Health Centre IV is a public health care facility owned by Kampala Capital City Authority (KCCA). It is in Kawaala, Rubaga Division, a neighbourhood within Kampala, Uganda's capital, and largest city, approximately 5km by road, north of Kampala Central Business District [64]. By September 2017, it was serving about 426 HIV infected adolescents and children and by 2021, it was serving 9,447 adults and children living with HIV [10]

3.2.3 Kisenyi Health Centre IV

Kisenyi Health Centre IV is a public health care facility under KCCA located along Mawanda II road, in Kampala. It is intended to serve 100,000 people within the health sub district. It offers a wide range of services extending from inpatient to outpatient services of which the HIV clinic is one of them [65]. It was serving 438 HIV infected children and adolescents by September 2017 and by 2021, it was serving 12,493 adults and children living with HIV [10].

3.2.4 Kiswa Health Centre IV

Kiswa Health Centre IV is a KCCA operationalized public health care facility located in Nakawa Division, Kampala district, 4.8 km east of Kampala Central Business District [66]. By September 2017, it was serving around 401 HIV infected children and adolescents and by 2021, it was serving 6035 adults and children living with HIV [10].



Figure 2: Map showing health centres in Kampala offering ART under KCCA *Source: Kampala HIV Fact Sheet 2021*

3.3 Sampling frame and sample size calculation for the sub-study

The sampling frame for this sub-study was 400 adolescents from the parent study who were aged 10-18 years as of March to September 2020 and attended 4 of the 5 HIV clinics in the parent study.

From this sample frame, sampling size was estimated using an online sample size calculator at 95% confidence level, significance level 0.05, the calculation was based on the premise that estimated population proportion of adolescents living with HIV on ART that have ever-used dental care services was 50% [67].

$$n' = \frac{n}{1 + (z^2 * p(1-p))/\varepsilon^2 N}$$

From this formula, z is the z score, ε is the margin of error, N is the population size and p is the proportion [67]. The minimum sample size that was required for this study was 197 adolescents [67].

3.4 Study participants of the parent study

In the parent study, three HIV clinics were purposively selected from 6 health facilities managed by KCCA providing ART services in Kampala [10]. One facility was selected from the National Referral hospital providing ART services and another was a Private Not for Profit. These were selected according to ART coverage, availability and accessibility [10]. Four of these clinics were public clinics under KCCA while one clinic was private-not-forprofit. The primary sampling unit was the clinic, and the cluster effect was considered in the sample size calculation and in analyses to provide precise estimates. Sample size calculation from five clinics was done considering a design effect of two. This was because the participants were sampled from five different clusters (clinics). This meant that there was a possibility that participants from the same clinic were likely to have similar characteristics (within variation of 0) and hence statistically, this would mean that a larger sample size would be required to factor for the variation between clusters (inter-cluster variation) to avoid an overestimation of precision of results [68]. In each clinic proportionate to size sampling of patients was applied. After purposive sampling, the participants were then stratified according to three age groups which represented the three strata. These included the following: stratum one; 2-7 years, stratum two; 8-12 years, stratum three; 13-18 years, totalling to 1041 participants from all the strata. From the parent study, out of the 1041 participants, 600 were adolescents aged between 10-18 years as of 2018 when the study started.

3.5 Study participants for the sub-study

This sub-study redefined the age bracket of 10 to 18 years as of 2020, such that those participants who had crossed the 18-age mark and those below 10 years were excluded. The exclusion of the 5th HIV clinic and redefining of age bracket as of 2020 provided a sampling frame for this study of 400 adolescents from which the study participants were selected. From March to September 2020, a total of 246 HIV positive adolescents out of the 400 eligible participants (50.5%) from the parent study, aged 10-18 years were purposively sampled into the present sub-study. Of the 246 participants that were contacted from the list of 10–18-year-old participants across the 4 clinics, 44 had either wrong contact numbers or their telephone numbers were not accessible. The 44 participants whose telephone contacts were inaccessible were automatically excluded from the study and hence not included in the

analysis. A total of 202 of the 246 selected adolescents participated in the present study. Participation rate was 82% (flow diagram figure 3)

Study participants were purposively selected according to availability and those who consented to participate were interviewed via a telephone call. Participant and caregiver consent was recorded via audio and stored on the server after providing all information regarding the study and the rights of the participant to withdraw any time they so wished without compulsion. Verbal consent was an affirmative statement from the participant and /or the caregiver that they were voluntarily willing to participate in the study. These affirmative statements from the participants were then recorded over the phone.

The participants had been registered with identity numbers that indicated their age and gender including telephone numbers at the time of initial participation in the parent study.

Of the 202 participants, 45 out of 81 adolescents were from Mulago, 61 out of 106 were from Kawaala, 45 out of 81 from Kisenyi and 51 out of 132 from Kiswa health Centres (*summarized in Table B.1*). The distribution of participants by HIV clinic was estimated after the data was collected.

Name of HIV Clinic	Number of Participants
Mulago ISS Clinic	45
Kawaala Health Centre IV	61
Kisenyi Health Centre IV	45
Kiswa Health Centre IV	51
Total	202

Table B. 1: Distribution of study participants according to HIV clinic

3.6 Inclusion criteria

- Adolescents who participated in the parent study and were 10-18 years at the time of the conduct of the sub-study
- Adolescents who were receiving ART treatment from Mulago ISS clinic, Kiswa, Kawaala and Kisenyi health Centres
- Adolescents whose telephone contacts were available and accessible at the time the study was conducted

3.7 Exclusion criteria

- Adolescents who were receiving ART care from Nsambya private-not-for-profit health facility
- Adolescents out of the 10 to 18 age brackets, HIV negative adolescents and adolescents with unavailable or inaccessible telephone contacts at the time the study was conducted



Figure 3: Flow diagram

3.8 Data collection, quality management and storage

3.8.1 Pilot Study

A pilot study was conducted involving 15 participants aged 10 to 18 years (not included among the 202 adolescents that officially participated in the main study). The purpose of the pilot was to check for suitability and usability of the questionnaire to make necessary adjustments before the start of the main data collection. The pilot study involved both telephone interviews and face to face interviews with a guided questionnaire. Only two out of the 15 participants had face to face interviews whereas all other participants had telephone interviews. The interviews were conducted in both Luganda and English using an Open Data Kit (ODK) form that had been structured and modified for the study [69]. All unclear questions that confused participants were either removed or modified to suit the study purpose prior to data collection.

3.8.2 Open Data Kit

Open Data Kit is an open-source software used in resource-constrained environments for data collection, management, and usage [70]. Data is collected offline and submitted to the server with internet connectivity. All data is collected on a mobile device in an offline mode which allows for full data control. Open Data Kit provides for different tools which include Collect, Aggregate, Voice and Build. Open Data Kit Collect is a mobile platform that allows data collection and handling. Open Data Kit Aggregate provides for data upload, storage, and transfer in the "cloud" as well as on local servers. Open Data Kit Voice employs automated phone prompts that users respond to utilizing keypad presses while Open Data Kit Build creates logic by the tools through drag-and drop application developing [71].

3.8.3 Interviews

This study was strictly based on telephone interviews due to the COVID-19 rules and guidelines [72]. Each interview lasted for about 30 minutes. A structured questionnaire (Appendix A & B) that guided the interview was uploaded using the Open Data Kit form [71]. The questionnaire used had been standardized for all participants. Two research assistants underwent a face-to-face training in using the Open Data Kit form and they were in addition

trained on how to conduct telephone interviews in both English and Luganda. They were each given a description of the study objectives and study outcome for standardization of the tool. They were both given electronic tablets Samsung Galaxy SM- T285 S# R52J60MZ22V and R52JB215X8TA and trained on how to use them. Both these devices were loaded with the standardized questionnaire in an ODK form and was used uniformly for all study participants. The questionnaire encompassed socio-demographic characteristics, factors affecting access to dental care services, personal dental health practices, general and HIV related concerns and attitudes and the outcome variable "ever-visit- the dentist" (Appendix A & B). At the start of the interviews, parents or caregivers were asked if the child was aware of their HIV serostatus. This was to enable a rephrase of sensitive questions for those who were not aware of their serostatus. This is because some parents or caregivers had withheld information regarding the adolescents' serostatus from them and told them other reasons for receiving frequent treatment. Therefore, questions that involved knowledge of dental care facility next to HIV Centre were directed to those that were aware of their HIV serostatus, whereas those participants who were not aware of their HIV serostatus (n=48) were asked a similar question rephrased to what their parents or caregivers had told them they receive medication for like cough, or any other thing as informed by the caregiver or parent. The research assistants were trained to be very keen on participants who were not aware of their HIV serostatus. (Appendix

A & B)

All questions relating to the HIV state, for example, if they had ever been afraid to go to the dentist because of their serostatus and fear of HIV spread were only specifically asked participants who were aware of their HIV serostatus.

The questionnaire was translated to Luganda from English by a local translator. Later five independent people (the main parent project study investigator, 2 research assistants and 2 pilot study participants) reviewed the accuracy of the language translation. Back translation from Luganda back to English was carried out informally through analysis of questions if they meant the same in English. Therefore, the telephone interviews were conducted mostly in the locally spoken language, Luganda, and a few in English. Andersen's behavioural model guided the selection of variables used to determine access and use of dental services among the selected group of participants [40].

The identity numbers given to participants in the parent study were maintained for consistency of findings, follow up and as an age guide to include only those between 10 and 18 years.

3.9 Measurements

3.9.1 Dependent variable

The dependent variable of this study was ever-use of dental care services which was phrased as "ever-visit the dentist" in the questionnaire. The participants were asked if they had ever visited the dentist with exception of the project participation. Response categories were given as yes (1) and no (0). Those who confirmed dental attendance were followed up with the question "when was your last visit to the dentist?" - responses were given as less than 6 months ago (1), 6-12 months ago (2), more than a year but less than 2 years ago (3), 2-5 years ago (4), more than 5 years ago (5). These responses were re-categorized into less than 1 year (1), more than 1 year but less than 2 years (2), and more than 2 years (3).

3.9.2 Independent variables

The various variables were defined according to Andersen's behavioural model into predisposing (socio-economic) factors, enabling factors, need related factors, and personal oral hygiene and dental practices.

3.9.3 Predisposing factors

These included socio-economic characteristics like age, gender, level of education, possession of household items, and home description.

The gender was categorized into male (0) and female (1); age was grouped into 2 groups; 10-13 years (1) or 14-18 years (2). The level of education had 6 options, and these included: Primary 1-3 (1), Primary 4-7 (2), Senior 1-4 (3), Senior 5 or 6 (4), Vocational courses (5) and those not attending school (6), and these were categorized into 3; those that had no formal school (0) and those that were attending primary level of education (1) and those that were attending secondary level of education (2). Vocational courses were categorized under secondary level.

The socio-economic status was assessed using a wealth index that assessed ownership of household items as assessed by Filmer et al [73]. The participants were asked if they possessed the items or not. A participant was recorded as possessing the item only if the item

was functioning. The items included television, electricity, bicycle, water, motor car, flush toilet, mobile phone, computer, radio, motorcycle, and refrigerator (Appendix A &B). Using principal component analysis (PCA), 5 quantiles were generated with 1 representing the poorest and 5 the richest quintile. These were further categorized into high quintile (1) and low quintile (0). Home description had 5 options which included very good (1), good (2), bad (3), very bad (4) and I do not know (5). These were categorized into 2; good (1) and bad (2).

3.9.4 Enabling factors

The enabling factors were assessed in terms of the participants' perception of the cost of dental services, fear of visiting the dentist, knowledge of location of dental facility either next to their residence or health facility, failure to get dental treatment because it was not part of the medical appointment, illness from other underlying medical conditions and information on the decision making in seeking dental care. Individual perception on dental visits was assessed in terms of cost, missing school, receipt of good dental care, time consumption, long queues at the dental facility, parent and teacher acceptance to the dental visit, usefulness of dental care and its impact on health. (Appendix A&B)

The questions concerning fear of going to the dentist had 3 options (1-3); I do not fear (1), I fear a little (2) and very fearful (3) and these were re-categorized into 2; "yes (1)" for both little fear and fear and "no (0)" for no fear.

The questions concerning fear of HIV spread, failure to receive dental treatment because it was not part of the medical appointment, and illness from other underlying medical conditions had responses with 4 options (1-4) and these included yes, several times (1), yes, a few times (2), no, never (3) and I do not know (4) and these were categorized into 2; "yes (1) or no (0)", "yes" for both several times and a few times and "no" for "no, never". All responses with "I do not know" were added to the most frequent response.

The questions on perception were assessed in terms of age bracket; those below 14 and above 14 years. Those below 14 years had responses of either "yes, no or I' do not know "while those above 14 years were asked similar questions but with varying responses according to the Likert scale of; "agree completely (1), agree partly (2), disagree partly (3), disagree completely (4) or I do not know (5). "The difference in responses was based on ease and intellectual ability differences among these age groups since they were questions based on how the adolescents perceived aspects concerning use of dental care services. (Appendix A &

B) The latter responses were categorized into 2; "agree (1) or disagree (0)" while the former into "yes (1) or no (0)."

The question regarding who is responsible for decision making in seeking dental care services had the following responses: parents (1), myself (2), my caregiver (3), my teacher (4) and I do not know (5). These were categorized into 2: parents/teachers/caregivers (0) and myself (1).

3.9.5 Need related factors

These included perceived overall general health, health of teeth and mouth, need for dental care services, satisfaction with the oral health condition, oral health symptoms like dental and mouth pain, bleeding gums and bad oral odour. (Appendix A & B)

Rating on general and oral (teeth and mouth) health had five options. These included poor (1), fair (2) good (3), very good (4) and excellent (5). These were further categorized into three; poor (1), fair (2) or good (3).

Satisfaction of oral health was assessed via four parameters, and these included very satisfied (1) satisfied (2), dissatisfied (3) and very dissatisfied (4) and these were categorized into two options either satisfied (1) or dissatisfied (0). "Satisfied (1)" category included responses of both very satisfied and satisfied while the "dissatisfied" category included responses of both dissatisfied and very dissatisfied.

3.9.6 Personal oral hygiene practices and aspects of use of dental care services

The variables assessed included frequency of toothbrushing and tooth brushing items. For those that had been to the dentist; variables that were assessed included: when they had last visited the dentist, the place for dental treatment, reason for the last dental visit, transportation means and cost to the dental facility, duration of time at the dental facility, communication with the dental team, attitude of the oral health providers, HIV, and dental treatment concerns. (Appendix A&B)

The frequency of toothbrushing had 6 responses (1-6). These included the following: never (1), several times a month (2-3 times) (2), once a week (3), several times a week (2-6 times) (4), once a day (5) and 2 or more times a day (6). These were then categorised into two; those who rarely brush (0) and those that brush daily (1).

Items used for tooth brushing /tools for tooth brushing assessed included soap, salt, urine, local herbs, ash, toothpaste, and nothing. These items were renamed in Excel workbook
2003(*xlsx), and each item dichotomized into yes (1) for those who used that item for brushing or no (0) for those who did not use that item.

For those who had been to the dentist, they were asked reasons for the last dental visit, type of dental health facility, travel cost to the dental health facility, duration at the dental health facility and attitude of the oral health care providers.

Reasons for the last dental visit included mandatory school check-ups or routine check-ups, emergency (tooth injury), emergency (toothache), having tooth (teeth) pulled, filling, root canal or others. were renamed and dichotomized into "yes (1)" for those whose responses were positive for a particular reason or "no (0)" for those with negative responses for a reason. Duration at the dental facility had 5 options (1-5); less than 1 hour (1), 1 to 2 hours (2), 3 to 4 hours (3), greater than 4 hours (4) and I do not know (5). These were then categorized into 3: less than 1 hour (1), 1 to 2 hours (2) or 3 and more hours (3). Average travel cost was assessed under 5 options (1-5). The options included the following: less than Ug. Sh. 4,000 (1), between Ug. Sh. 4100 – 10000 (2), no money spent (3), more than 10000 (4) and I do not know (5). These were categorized into; no money spent (0), less than Ug. Sh. 4,000 (1), between Ug. Sh. 4100 – 10000 (2) or more than 10000 (3). Attitude of the oral health care providers was also assessed 5 options (1-5), and these included very good (1), good (2), average (3), below average (4) and I do not know (5) that were categorized into 3; good (1), average (2) or below average (3). "Very good (1) and good (2)" responses were put under the "good (1)" option.

NB: All "I do not know" responses were added to the most frequent categories.

3.9.7 HIV-related dental care experiences

Participants who were aware of their HIV serostatus and had ever been to the dentist were asked specific questions particular to HIV and their dental experience.

They were asked if the dentist they visited had ever inquired of their HIV serostatus before offering dental services, they were also asked if they had ever withheld their HIV status from the dental care provider.

Other questions included if they had ever felt inconsistencies/differences in dental care service delivery between them and people they knew that had a negative HIV serostatus, inquiry into any dissatisfaction in dental care delivery conditioned on their serostatus. The responses for these questions were only 2 options which were either yes (1) or no (0) and finally they were asked their perception about the dentist that offered dental care. The options for this question

included excellent (1), good (2), fair (3) and poor (4). (Appendix A&B) These were recategorized into 3; poor (1), average (2) and good (3).

3.10 Statistical methods

Data was analysed using Statistical package Stata/SE 17.0 [74]. Categorical variables were summarized as percentages while continuous variables were summarized with mean, medians/range. Cross-tabulations were done using Fischer's exact test [75]. Fischer's exact test was used because it reported be the most reliable and valid test for small sample sizes especially in cells having frequencies less than five. In this sub-study, Fisher's exact test was preferred over chi squared test because it gives the exact estimates and not an approximation [76, 77]. Simple modified Poisson regression was used at bi-variate analysis while multivariable modified Poisson regression was used to determine factors associated with everuse of dental care services at 95% confidence interval and at 0.05 level of significance. The measure of association was the Incidence risk ratio (IRR) from the multivariate modified Poisson model that was interpreted as the prevalence ratio (PR) for this sub-study because it was a cross-sectional study. At multivariate analysis stage, all variables related to predisposing, enabling, related factors and personal oral hygiene and dental practices with a more likely association with ever-use of dental care services (p-value ≤ 0.2) in unadjusted analyses were included in the model. However, none of the variables under personal oral hygiene and dental practices had a likely association with ever-use of dental care services in unadjusted analyses, hence excluded in the multivariate model analysis.

In addition, the 4 clusters (which represented the 4 different clinics the participants belonged) were adjusted for using clustered robust standard errors incorporated in the Poisson regression model. Subgroup analyses were also carried out for age categories 10-13 and 14-18 for certain variables under enabling factors of Andersen's behavioural model that had different responses.

3.11 Ethical considerations

Ethical permission was obtained from Makerere University Institutional Review Board, School of Health Sciences Research and Ethics Committee (MakSHSREC) and Uganda National Council of Science and Technology (UNCST), reference number is 2017-080. Permission was also got from Kampala Capital City Authority since the clinics used for the study were under their governance and control. Ethical permission was also obtained from the Norwegian Regional Ethics Committee (REK), reference number is 466785.

Prior to participation, all parents, or caregivers of adolescents between 10 and 17, and adolescents of 18 gave a verbal consent and verbal assent was provided in addition for those between 13 and 17.

Verbal consent was obtained from the parents or caregivers of the adolescents below 18 years and verbal assent obtained from all the adolescents (13-17 years) and audios recorded. The parents or caregivers' names that consented their children to participate in the study were recorded and the dates the interviews were held. Before the interviews, consent was first obtained from parent or caregiver for all adolescents below 18 years, whereas those that were 18 gave consent individually. For those between 13 and 17 years, verbal assent was obtained after parent or caregiver consent. Consent involved information about details of the reason for the ongoing project, any risks and benefits, voluntary participation, privacy, and confidentiality. Each participant was given liberty to withdraw from the study at any time if they so wished.

For anonymity of personal data, each participant was recognized by an ID number from the parent project that was made up of age, gender, HIV clinic and number at the time of recruitment. The key for binding the ID number of each participant was kept under a secure server of the parent study.

3.12 Study Risks and Benefits

Participation in this study had no possible risks involved. Privacy and confidentiality of participants' personal information were effectively maintained through data anonymity and use of telephone interviews.

As a benefit to the study, the parent study provided participants with free dental examination and treatment of urgent dental concerns by the participants. This sub-study also offered free telephone consultations about dental health issues to the participants.

4.0 Results

4.1 Distribution of study variables among 10–18-year-old adolescents living with HIV on ART according to gender

Table 1 depicts the distribution of study variables in total and according to gender. A total of 202 adolescents, aged between 10 and 18 years participated in this study, with participation rate 202/246 (82.1%). The median and mean age were 13- and 13.6 years, respectively while range was 10 to 18 years. The proportion of males was 55.9% (113/202) whereas the proportion of females was 44.1% (89/202). Five percent (11/202) of the participants reported having no formal education. More females were attending primary level of education compared to their male counterparts 75.3% (67/89) versus 57.5% (65/113). Overall, 60.4% (122/202) of the participants were in the low quintile category with more males coming from the low quintile families compared to females, 66.4% versus 52.8%. In general, most participants 58.9% (119/202), described their homes as being in good condition. Corresponding estimates among males and females were 54.9% (62/113) and 64.0% (57/89). Majority of the participants, 90.1% (182/202), were not afraid of going to the dentist, with more males (10.6%) afraid of going to the dentist compared to females (9.0%). More than half of the participants, i.e., 68.8% (139/202) were aware of a dental facility next to the HIV care centre while 4% (8/202) agreed that there was failure to get dental treatment because it was not part of the medical appointment.

In general, 52.5% (106/202) rated the general health of their teeth and mouth as being good with 51.3% of males versus 53.9% of females reporting good oral health. Among the study participants, 89.6% (181/202) reported that their parents or caregivers/teachers were primarily responsible for decision making in seeking dental care services. Ninety-eight out of 202 (48.5%) participants were satisfied with and happy with the health of teeth and mouth, 69.8% (141/202) felt a need for dental treatment while majority 74.7% (151/202) of the participants perceived their overall general health as good. More males, i.e., 80/113 (70.8%) perceived they needed dental care compared to females, i.e., 61/89 (68.5%). Of the 202 participants, 38.6% reported they had dental and mouth pain while 21.8% reported bleeding gums. The prevalence of ever-use of dental care services among the study participants was 12.4% (25/202). Seventeen percent of the participants (35/202) reported bad oral odour. More males (19.5%) compared to females (14.6%) reported bad oral odour. Majority of the participants,

i.e., 96.5% (195/202) used toothpaste for brushing and 24.3% (49/202) often used ash for brushing. More males (97.3%) versus females (95.5%) used toothpaste for brushing.Occasionally participants used soap (8.4%) and salt (21.3%) for brushing as shown in Table 1.

4.2 Ever-use of dental care services among 10-18-year-old adolescents living with HIV on ART according to predisposing factors

Table 2 depicts bivariate analysis of ever-use of dental care services by predisposing factors in terms of socio-demographic characteristics. A total of 60% males versus 40% females reported ever-use of dental care services. Among the age category of 14-18 years, 56% reported ever-use of dental care services whereas 44% reported ever-use of dental care services in the 10-13 age group. Among participants with no formal education the prevalence of ever-use of dental care was 4% compared with 52% and 44% among participants with primary level and secondary level, respectively. A total of 60% versus 40% of participants with good and bad home conditions confirmed ever-use of dental care services. A total of 64% versus 36% of adolescents in respectively low and high socio-economic status quintile reported ever-use of dental care services. As shown, ever-use of dental care services did not associate significantly with predisposing factors in terms of socio-demographic characteristics despite differences between the groups.

4.3 Ever-use of dental care services among 10-18-year-old adolescents living with HIV on ART according to enabling factors

According to Table 3, ever-use of dental care services was statistically significantly associated with failure to get dental treatment because it was not part of the medical appointment and illness from other underlying medical conditions. Eighty percent versus 20.0% (p<0.001) of participants who respectively, disconfirmed and confirmed failure to get dental treatment because it was not part of the medical appointment reported ever-use of dental care services. In addition, 80.0% versus 20.0% (p<0.001) of participants who respectively, disconfirmed and confirmed illness from other underlying medical conditions reported ever-use of dental care services. Other enabling factors in terms of being afraid of going to the dentist, the knowledge of a dental facility next to their residence, and responsible person in decision making in seeking dental care services were not statistically significantly associated with ever-use of dental care services.

4.3.1 Ever-use of dental care services among 14-18-year-old adolescents living with HIV on ART according to enabling factors

As depicted in Table 3a.1, 97 participants were between 14 to 18 years of age. In this age group, 72.2% (70/97) had a perception that the dental services were costly and visiting the dentist would make them miss school. Seventy-one out of 97 participants (73.2%) had a perception that dental services were time consuming while 77.3% (75/97) reported that there would be long queues at the dental facility if they visited the dentist. In unadjusted bivariate analysis, a total of 100% (14/14; p=0.04) of participants who reported long queues at the dental facilities confirmed ever-use of dental care services. In addition, a total of 50% (7/14) versus 50% (p=0.06) of participants who respectively disconfirmed and confirmed that they think dental services are costly reported ever-use of dental care services.

4.3.2 Ever-use of dental care services among 10-13-year-old adolescents living with HIV on ART according to enabling factors

As shown in Table 3b.1, 105 participants were between 10 to 13 years of age. In this age group, 80% (84/105) had a perception that the dental services were costly and 89.5% (94/105) reported that visiting the dentist would make them miss school. Sixty-nine out of 105 participants (65.7%) had a perception that dental services were time consuming while 76.2% (80/105) reported that there would be long queues at the dental facilities if they visited the dentist. All participants between 10-13 years reported that parents would allow them to visit the dentist if they had dental problems (not shown in the table).

A total of 90.9% versus 9.1% of adolescents who respectively confirmed and disconfirmed that dental services are costly reported ever-use of dental care services compared to those that said no. A total of 100% participants that reported ever-use of dental care reported that paying a visit the dentist would make them miss school. However, no enabling factor was statistically significantly associated with ever-use of dental care.

4.4 Ever-use of dental care services among 10-18-year-old adolescents living with HIV on ART according to need related factors

As depicted in Table 4, ever-use of dental care services was statistically significantly associated with the following need related factors, perception of overall health in general, perception of health of teeth and mouth, satisfaction with health of mouth and teeth. Totals of 36.0%, 32.0% and 32.0% of participants having respectively, bad, fair, and good perceptions of health of teeth and mouth reported ever-use of dental care services respectively (p<0.05). Totals of 76.0% versus 24.0% (p<0.001) being respectively, dissatisfied and satisfied with health of mouth and teeth confirmed ever-use of dental care services. Under perception of general health, totals of 12.0%, 32.0% and 56.0% of participants reported having respectively poor, fair, and good perceptions of health of teeth and mouth reported ever-use of dental care services ever-use of dental care services.

4.5 Ever-use of dental care among 10-18-year-old adolescents living with HIV on ART according to personal oral hygiene and dental practices

As depicted in Table 5, a total of 36.0% versus 64.0% of participants who respectively reported rarely and daily toothbrushing confirmed ever-use of dental care services. Of the 202 participants, 96% versus 4% who respectively confirmed and disconfirmed use of toothpaste for tooth brushing reported ever-use of dental care services. Sixteen percent of the participants who reported use of ash for tooth brushing confirmed ever-use of dental care services. According to table 5, no variable under personal oral hygiene and dental practices was statistically associated with ever-use of dental care services despite differences between groups.

4.6 Ever-use of dental care services among 10-18-year-old adolescents living with HIV on ART according to predisposing, enabling, need related and behavior related factors: multivariable analysis

As depicted in Table 6, gender and age were forced into the multivariable model in spite that none were significantly associated with ever-use of dental care services in unadjusted analyses. The variables included in the final model were gender, age, fear of going to dentist, failure to get dental treatment because it is not part of the medical appointment, illness from other underlying medical conditions, perception about general health of teeth, dental and mouth pain, satisfaction of dental state and perception about overall general health.

Table 6 summarizes the regression analysis of ever-use of dental care services using modified Poisson regression models. Gender and age were not statistically significantly associated with ever-use of dental care services. Compared to participants that were not afraid, those who were afraid were 2.62 times more likely (PR 2.62, 95% CI 1.04-6.60) to report ever-use of dental care services. In comparison to participants who perceived their health of mouth and teeth to be bad, those that had a fair perception were 0.78 times less likely (PR 0.22, 95% CI 0.05-0.98) to report ever-use of dental care services. Those who had good perceptions about their health of mouth and teeth were 0.69 (PR 0.31, 95% CI 0.08-1.22) times less likely to report ever-use of dental care. On the other hand, those who replied yes to failure to get dental treatment because it is not part of the medical appointment were 3.16 times more likely (PR 3.16 95% CI 2.41-4.16) to report ever-use of dental care compared to their counterparts who said no.

The multivariate model was tested for goodness of fit using Pearson Chi-squared goodness of fit and a pseudo-R squared value. Pearson Chi-squared goodness of fit test statistic of the model was 183.12 at 190 degrees of freedom with a p-value of 0.63. The pseudo-R squared was 0.17. The Pearson Chi-squared goodness of fit test is defined as a statistical test that is used to assess if the observed frequency distribution of categorical data follows the anticipated or theoretical distribution [78].

4.7 Frequency distribution of oral health and related characteristics among 10-18 years old adolescents living with HIV on ART and who had ever visited the dentist

Oral health and related characteristics were separately explored among participants who confirmed ever having been to a dentist (n=25). As depicted in Table 7, of the participants that ever visited the dentist, more than half 56(14/25) went there because of a toothache. A majority had tooth extraction or "having teeth pulled" as the main reason for the last dental visit i.e., 84(21/25). Seventy six percent (19/25) of the participants that had ever-used dental care services were aware of their HIV serostatus. A majority, 60% (15/25) sought dental care from public facilities while 40% (10/25) sought dental care from private facilities. When asked about transportation to the dental facility, 52% (13/25) reported using bus or taxis, 24% (6/25) of the participants reported walking to the dental facility, 16% (4/25) people reported use of motorcycles while 8% (2/25) people rode bicycles to the dental facility.

When asked about average travel cost, 40% reported a cost between 4100 to 10,000 Uganda shillings, 32% more than 10,000, 16% less than 4,000 Uganda shillings and 12% spent no money on transport to and from the dental facility. Results summarized in table 7 below.

4.8 HIV-related dental care experiences among 10–18-year-old adolescents who had ever visited the dentist and were aware of their HIV serostatus

Among the participants that were aware of their HIV serostatus and visited the dentist (n=19), 26.3% (5/19) reported that the dentist inquired of their HIV serostatus before offering dental services. Five percent (1/19) of the participants reported withholding their serostatus from the dental health care provider. About 10.5% (2/19) participants were dissatisfied with the quality of dental care rendered to them due to their serostatus. Sixteen percent (3/19) of the participants felt that the quality of dental care rendered to them was different from their seronegative counterparts. Sixty three percent (12/19) had a good perception on the dentist that offered dental treatment. The results are summarized in Table 8.

5.0 Discussion

The discussion summarizes the main findings of this thesis, then discusses its strengths and limitations, and the theoretical considerations regarding Anderson's behavioural model. The present findings are compared to findings of similar studies published previously. Finally, the present findings are discussed, and recommendations are given for further research, interventions, and changes in policy.

5.1 Summary of findings

The prevalence of ever-use of dental care services was low among Ugandan adolescents 10-18 years of age investigated in this study and amounted to slightly above 10%. In accordance with Andersen's behavioural model, the main exposures of ever-use of dental care services were defined in terms of predisposing, enabling, need related factors and personal oral hygiene and dental practices [40]. The findings from bivariate analyses revealed that none of the variables included in predisposing factors and personal oral hygiene and dental practices were significantly associated with ever-use of dental care services.

In the regression analyses including all the conceptual factors from Andersen's model; enabling factors that were found to be statistically significantly associated with ever-use of dental care services in the multivariate analysis were fear of going to the dentist and failure to get dental treatment because it was not part of the medical appointment. Those who were afraid of going to the dentist were more likely to have ever- used dental care services. The participants who confirmed failure to get dental treatment because it is not part of the medical appointment were also more likely to have ever-used dental care services. Among need related factors, perception about health of teeth and mouth was found to be statistically significantly associated with ever- use of dental care services. Those that perceived their health of teeth and mouth as fair and good were less likely to have used dental care services than their counterparts who perceived oral health as bad.

The Andersen's behavioural model explained only 17% of the variance in ever-use of dental care services by the study participants. This indicates that many other variables not included in the model are important determinants of ever-use of dental care services among adolescents living with HIV. However, a Pearson Chi-squared goodness of fit test statistic of 183.12 at 190 degrees of freedom at p-value of 0.63 revealed that the data had a favourable fit to the model.

In terms of relative importance, enabling factors were more strongly associated with ever-use of dental care services followed by need related factors in terms of perception about health of teeth and mouth which was only marginally significantly associated with ever-use of dental care services.

Despite differences in socio-demographics of the participants in this study, predisposing factors and personal oral hygiene and dental practices were the least important factors in relation to ever-use of dental care services.

The enabling factor that was statistically significantly associated with ever-use of dental care services among those above 14 years (14-18) was long queues at the dental facilities. All the participants that confirmed long queues at the dental facility reported ever-use of dental care services. Among the 10-13 age group, no enabling factor was found to be statistically significantly associated with ever-use of dental care services. Among the group that had ever been to the dentist, tooth extraction or "having teeth pulled" was the main reason for the last dental visit.

5.2 Strengths

5.2.1 Study novelty

A strength of this study is that it provided information about ever-use of dental care services and its determinants in a vulnerable group of adolescents living with HIV on ART in Uganda where information about use of dental care services is rare also in the general population. This study is the first of its kind in Uganda targeting adolescents with a broad age range from 10 to 18 years of age, living with HIV and taking ART.

5.2.2 Study procedure and implementation

This sub-study had an advantage of sharing infrastructure with and being part of a larger parent study. Being part of the parent study facilitated recruitment of participants and the entire data collection process. All the variables used in this sub-study were pilot tested and found to be reliable and valid for use. The use of interviews as a means of data collection had a strength of preventing participant confusion as it was easier to clarify where questions were not understood in comparison to self-administered questionnaires [79]. In addition, use of mobile phones enabled participants to address sensitive questions about HIV and dental care services without feeling victimized and promoted privacy and thus potentially increased the response rate [80]. The use of an electronic data collection tool which was the Open data kit was another strength as it minimized human error during the data collection process through an authentication process at the data entry stage. It also eliminated the possibility of item nonresponse as the tool was designed in such a way that one couldn't respond to another question before answering the previous one [81]. This study had no missing data which was an additional strength. This study was of cross-sectional design and hence had the advantage of being cheap to conduct, less time consuming and allowed a quick data collection process that established a basis for further research [82].

5.2.3 Statistical analysis

Another strength is the choice of novel statistical methods. Because the prevalence of everuse of dental care services was larger than 10% (prevalence of ever-use of dental care was 12.4%), ever-use of dental care services is considered a less seldom outcome and the more commonly use of ordinary logistic regression for binary outcomes with odds ratios could have provided an overestimation of the associations estimated. Thus, Poisson regression was preferred over ordinary logistic regression [83]. Moreover, since the study had a binary outcome and not counts, the Poisson regression utilized was modified to use robust standard errors instead of default standard errors. This further minimized the bias created by model misspecification [84].

The use of a multivariate model that included all variables from predisposing, enabling and need related factors that were found to be significantly associated with ever-use of dental care services in unadjusted analyses, enabled identification of the relative and independent importance of the determinants in relation to ever-use of dental care services among the study participants. The use of a multivariable model in addition, enabled inclusion of those variables that were associated with ever-use of dental care services independent of all other factors included in the multivariable model.

5.2.4 Theoretical model considerations

The use of a theoretical framework guided the selection of influencing factors, their independent relationship with ever-use of dental care services and their relationship with each other. The use of a theoretical framework to identify determinants of ever-use of dental care services was a powerful tool. Andersen's behavioural model for this study was a good model for the suggestion of influencing factors of the psychosocial and biological aspects of ever-use of dental care services. This model describes reasons behind imbalances in access and use of dental care services based on gender, age, socioeconomic status (predisposing factors), factors that enable services to be accessed (enabling factors) and individual's perception of the need of dental care services (need related factors). This model also allows an incorporation of environmental factors and how they influence access and use of dental care services [85]. For example, from this study, factors that compromise access to dental care were explored by travel costs and means of transport to the dental facilities.

Andersen's behavioural model also suggests how the social factors like family and friends influence an individual's decision to seek and recognize oral health needs therefore making it a good model for oral health seeking behaviour. For example, in this study, participants were asked about who the decision makers were when it came to seeking dental care services. Furthermore, it considers the role of health professionals and how they impact or influence the use of health services which in this case are oral health services [86]. In this present study, participants who had ever-used dental care services were asked about their experiences at the dental facility. The model elaborates the risks an individual has before onset of oral disease based on location, social class, medical status, and also covers individual perception of illness [39]. This is evidenced through predisposing factors that incorporate socio-demographic characteristics of individuals like age and education level and need related factors that covers perception of need of dental care services.

The use of a theoretical framework like Andersen's behavioural model provided a foundation from which the sub-study variables were chosen and hence contributed to the validity of the study.

5.3 Limitations

5.3.1 Study design

This study was of cross-sectional study design and hence it did not set out to establish causal relationships but just risk indicators between the variables tested and ever-use of dental care services. In addition, it could not assess the relationships that occur over a period of time [82]. The measure of "ever-use of dental care services" attributes to the lifetime prevalence of use of dental care services. However, this measure was assessed cross sectionally at one point in time in this study; between March to September 2020. The other limitation is the temporality effect. It's hard to ascertain whether ever-use of dental care services happened before or after the different variables in this study hence difficult to determine the "cause-effect" relationship [82].

5.3.2 Andersen's behavioral model

The Andersen's behavioural model does not have standardized variables categorized under predisposing, enabling, need or personal health practices in different studies. Although this study encompassed the concepts suggested by Andersen's model, these concepts are broadly defined, overlap to some extent and the model do not define a fixed set of variables to reflect the predisposing, enabling and need related factors [87]. Thus, an unambiguous selection of variables into the various concepts of this model is not possible. This leads to a lot of variations among studies in terms of what variables are included in the concepts of

Andersen's model and makes it difficult to compare the present findings with those of other studies. In this study however, variables to measure predisposing, enabling and need related factors were selected with reference to previously carried out studies in low-income countries and factors of interest in line with the research question and objectives. Nevertheless, despite its drawbacks, Andersen's behavioural model has been frequently used across various cultures in addition to the other theories of health-and social behaviour for instance Theory of planned behaviour [88] and the Health belief model [89].

5.3.3 Information bias and selection bias

In this study, information bias through recall and social desirability bias, including selection bias could have threatened the internal validity through the possibility of a systematic error [90]. Internal validity is best defined as the ability of the study to measure what it intends to measure. It is a true representation of exposure-outcome association of a study due to accuracy of study methodology from study design, implementation and analysis [91]. The study findings could have been prone to recall bias since participants were asked about everuse of dental care services which implies lifetime use of dental care services [92]. It is plausible that some could have forgotten childhood experiences. Moreover, the parent study had offered free dental screening and emergency treatment to the participants which some could have confused as a previous dental experience. This was however minimized through the phrasing of questions by specifying "with exception for research purposes." Nevertheless, this could have overestimated the prevalence of ever-use of dental care services. For those that ever-used dental care services, all information collected was solely dependent on self-reports from participants of their last dental visit and reason for the visit and not dental visit records which could have also compromised the quality of information collected.

Another potential information bias was social desirability bias which could also have threatened the internal validity of study findings [92]. This could not be ruled out since participants had been sensitized on proper oral hygiene during the ongoing parent study, hence the possibility of giving the ideal personal oral hygiene answers versus the reality answers during the study interviews.

There was a possibility of selection bias in this study which was created through the sampling process, insufficient sample size, and unit non-response. This study used purposive sampling according to telephone availability and accessibility and selected adolescents taking ART from purposively selected HIV health care facilities in Kampala. In addition, this study had a

unit non-response rate of 18% due to unavailability or inaccessibility of participants' telephone contacts. The unavailability of some of the participants' telephone numbers had a negative effect on the recruitment of participants for this study. This led to inclusion of a limited number of participants that were less than the required calculated sample size found to be satisfactory to infer associations between the various variables and ever-use of dental care services. It is therefore plausible that some of the insignificant findings were a consequence of low statistical power for the current study due to the possibility of a type II error resulting from an insufficient sample size [93].

The possibility of selection bias could also have threatened the external validity of this study in addition to its effect on internal validity.

5.3.4 Precision of study findings and reliability

The insufficient sample size of this study could have compromised the precision of the study findings as shown by the wide confidence intervals [94]. The confidence intervals were further widened due to the few clusters (four clusters) selected as participants belonged to 4 different clinics or primary sampling units. The cluster effect, or the consequence of the fact that individuals belonging to the same cluster is not totally statistically independent, was considered in the sample size calculation and adjusted for in the analysis. Reliability of a study is defined as the ability to produce similar results when repeated measurements are taken in a relatively short time period under the same conditions using similar methods [95, 96]. Reliability was enhanced through training of research assistants and use of a standardized questionnaire uploaded on an ODK form to control for inter-observer variation [95]. However, a test-retest reliability check for consistency over time was not carried out [96].

5.3.5 Generalizability of study findings

The external validity or representativity of a study is the ability of the results of the study to be extrapolated to a larger population due to the use of a randomly selected sample that is representative [97]. The purposive sampling method utilized in this study may limit the generalizability of the findings to a larger population of adolescents living with HIV and taking ART in the same age group. Thus, the sample of adolescents investigated might not be representative of adolescents living with HIV and taking ART in Kampala or in Uganda.

However, the HIV centres were selected according to ART coverage, i.e., the centres that offer ART to the highest number of people living with HIV in Kampala were considered for the parent study [10]. It cannot however be ignored that adolescents living with HIV in Uganda are on the increase. Just in 2020, there was an approximate of 11,000 new HIV infections among adolescents (10-19) in Uganda as a whole [98]. In addition as of 2021, Kampala alone had 173,247 adults and children on ART [10].

The unit non-response could also have threatened the external validity of study findings. This is because the relationship between the various variables and ever-use of dental care services could not be determined of those that didn't participate in the study [90]. In summary, due to possible unit non-response, purposive sampling of participants at both individual and clinic level, and insufficient sample size the results of this study may not be inferred to a larger population of adolescents living with HIV and taking ART in Kampala, Uganda. Nevertheless, the present study findings can be a point of departure for further and larger studies focusing on adolescents living with HIV.

The other potential bias would spring from the healthy user effect. This means the tendency of participants involved in certain preventive behaviours to adopt other health behaviours concerned with prevention as a means of health promotion [99]. However, this is least likely in this study as our findings indicated that among those participants that had ever visited the dentist, only one participant out of 25 reported routine dental check-up as a reason for the last dental visit.

5.4 Comparison with other study findings

5.4.1 Comparison with other studies reporting prevalence of use of dental care services

According to Table 1, a relatively small proportion of HIV positive adolescents that participated in this study reported ever-use of dental care services (ever visited the dentist) amounting to 12.4%. This study finding is only slightly lower in comparison to results from a study among adolescents (12-18) living with HIV on ART in the Henan province of China in which 19% confirmed to have ever been to the dentist [100]. This Chinese study was carried out in a rural part of Henan province in China with majority of people living with HIV due to contamination of blood plasma in the 1990s [101]. The differences could be attributed to the difference in the economic situation of the two countries, the distribution and accessibility of

dentists, and the regions where the two studies were conducted [102, 103]. This study was carried out in Kampala, the capital city of Uganda that is highly urban compared to the rural setting of Henan province of China [60, 100]. Nevertheless, China is an upper middle income country compared to Uganda which is a low income country [104, 105]. This may further describe the variations in the definition of rural settings of both countries. Whereas our study found low levels of ever-use of dental care services, some African studies found varying levels compared to that in our study. For example, studies conducted among adults living with HIV in Nigeria, Uganda, and Tanzania (aged 15-80) reported rates of dental care utilization amounting to 8%, 9% and 18.5%, respectively [38, 106, 107]. The differences in the level of use of dental services could be explained by differences in both the study populations, study settings, health financing systems, study designs, and outcome measures. The study carried out among adults living with HIV in Nigeria had a measure of use of dental care services before and after contracting HIV [106]. Subsequently, the study carried out in Uganda had a measure of lifetime use of dental care services while that carried out in Tanzania had a measure of visiting the dentist due to oral health problems [38, 107]. On the other hand, our study had lower levels of use of dental care services than a study carried out among adolescents (10-19) from the general population of unknown serostatus, in Nigeria and Uganda (13-19) which showed use of dental care services to be 40.6% and 44% respectively [108, 109]. The other difference in study findings would have arisen from the measure of the outcome variable, ever-use of dental care services in this study versus the other studies. For example, in the study by Okullo et al, the measure of use of dental care services referred to the past 2 years and not a lifetime [109]. In addition, the latter studies were carried out in the general adolescent population and not the HIV population on ART [108, 109]. However, these findings further emphasize imbalances in use of dental care services among the different study populations. None the less, the observed low levels of use of dental care services among the HIV positive adolescents in this study might accelerate the already big burden of unmet needs for dental care services in the Ugandan adolescent population. It may be difficult to compare the low level of use of dental care services in this study population to other previous studies due to the cultural differences, differences in study populations according to HIV status, medication control, and age.

It should also be noted that the current study findings are contrary to our expectation that in the presence of HIV infection, there would be more frequent use of dental care services compared to the general population due to a higher prevalence of oral diseases among HIV infected compared to non-HIV infected adolescents. This expectation follows reports that more than 70% of people living with HIV have at least one oral manifestation in the course of the disease [106, 110]. This notion is further evidenced by a study among South African adults living with HIV that revealed that about 62.3% of study participants presented with multiple oral health problems [111]. Hence HIV infection is a risk factor for oral problems and diseases. In addition, another study carried out among HIV infected adolescents (10-19), on ART in South Africa reported a prevalence of dental caries of approximately 57%. [112]. A few studies in Uganda have showed a high prevalence of dental caries in adults living with HIV on ART amounting to 67% and 83.7% [23, 38] and a treatment need of 96% [38].

In addition, it may also be reasoned that the low levels of ever-use of dental care services identified in this study may result from limited awareness about dental care services in the study group investigated. Low awareness levels may exist because there is no HIV dental integrated health care system in Uganda and thus many of the patients that seek care at HIV care facilities may be unaware of the services. Uganda is equally faced with a challenge of just a handful of dentists, approximately 300 serving a population of over 44 million Ugandans. In addition, most of the dental clinics are privately owned hence quite expensive to afford dental care services for the marginalized groups [113]. Therefore, the low levels of ever-use of dental care services may be attributed to the limited availability of dentists and a generally compromised access to the dental facilities. A recent study in 2020 revealed that of the 97 districts in Uganda, there was no public dental facility in 15% of the most rural areas of the country [114]. The other reason for low levels of ever-use of dental care services would spring from the fact that hope is lost once an individual has been diagnosed with HIV [20]. This in turn leads to a lack of interest in general state of oral health due to the perception of premature death or a short life span [20].

5.4.2 Comparison with other studies reporting on predisposing /sociodemographic factors associated with use of dental care services

According to Table 2 and 6, predisposing factors such as age, gender, and education (Table 2) were not associated with ever-use of dental care services. Other studies have reported similar findings, as for instance study of adolescents and young adults living with HIV in China as well as a study from Northern California focusing on adult women living with HIV [25, 100]. In a study among adolescents of unknown serostatus, in Uganda, showed that age was not

likely to be associated with receipt of oral care although older participants were more likely to be dissatisfied with oral health than the younger participants [109]. Contrary to our study, a study carried out in the United States of America among adults living with HIV showed that older age groups were more likely to be retained in oral health care compared to the younger age groups [115].

Similar to our study findings, is a study carried out among adults, of low income, living with HIV in South Florida that reported no association between gender and use of dental care services [31]. However, contrary to our study findings is a study carried out among adult dental patients of both known and unknown HIV serostatus in Khartoum, Sudan [47]. This mentioned study revealed that females were more likely to use dental care services compared to the male counterparts [47].

Researchers have further argued that education is a factor associated with use of dental services which was not the same in our study findings. In the general adolescent population of unknown serostatus in Lesotho, participants who had received some level of oral health education were more likely to visit the dental facility in the previous year compared to those with little or no oral health education [116]. Another study among adults living with HIV in South Florida reported that participants who had more than a high school education were more likely to use dental services compared to their counterparts who had not attained the same [31]. Contrary to this, a study in Nigeria among adults living with HIV revealed that the highly educated did not seek dental services after testing positive for HIV [106]. This could be due to possible stigma associated with HIV contraction and fear of job loss as stated by Adedigba et al [106]. A comparable study among the general adolescent population in Uganda, of unknown serostatus revealed no association between education status and use of dental care services despite differences in satisfaction of oral health state across education levels [109]. Another study with similar findings was that among caregivers of children living with HIV that showed no association between the caregiver's level of education and use of dental care services [33]. It should be noted, however, that the mentioned studies are not completely comparable studies to the present one due to differences in study populations by age, culture, health status and settings. However, given the contradictions in findings, the role of these demographics on use of dental care services among people living with HIV remains unclear.

From the present study findings, it could be explained that the low sample size utilized in this study could have ignored the differences that could exist between the different categories. The other reason could be generated that in the adolescent population, the decision-making process in seeking dental care services is mainly controlled by either parents, caregivers, or teachers (Table 3). This could further elaborate why neither age nor gender of the study population would influence ever-use of dental care services.

5.4.3 Comparison with other studies reporting on enabling factors associated with use of dental care services

Enabling factors associated with ever-use of dental care services are presented in Table 3 and 6 for the total study group and in Table 3a.1 and 3b.1 for the older (14-18 years) and younger (10-13 years) study group. As can be seen based on the multiple variable analyses (Table 6), ever-use of dental care services was found to be associated with fear of visiting the dentist among the 10 to the 18-year-old- participants. The participants who feared visiting the dentists were more likely to use dental services compared to their counterparts who did not confirm dental fear. This finding is inconsistent with many other studies in both Africa and America focusing adults living with HIV [20, 25, 106, 117]. The latter studies showed that participants who feared dentists were less likely to use dental care services than their counterparts who had no fear. Fear is one of the most commonly identified barriers to use of dental care services both in general populations and subpopulations of diseased people [20, 25, 106, 117, 118]. The difference in our study findings may be attributed to differences in the age of study populations and cultural differences. It is common that the HIV population is always in constant interaction with medical personnel due to their increased need for health services and thus could be less scared of the personnel than of the procedures and instruments [119].

From the present study findings, it could be explained that most participants only visited the dentist as an emergency option due to pain, and so even if they feared visiting the dentist, they were still more likely to visit the dentist due to other reasons. In addition, the present study findings could be explained that individuals with dental fear might also have poorer oral health and hence a greater need for dental care services [118, 120]. This would in turn accelerate the burden of oral health problems on the health system as well as reducing the individual oral health quality of life.

Considering the older group of participants, 14-18 years (Table 3a.1), those who reported that visiting the dentist was time consuming were more frequent ever-users of dental care services compared to those who denied that dental care services were time consuming. This might reflect differences in need for dental care services among this category of participants. This finding is in line with another qualitative study conducted among adults living with HIV in Florida [20]. The participants noted that when they got appointments to see a dentist, they had to wait for long hours at the facility before being worked on [20].

From the present study findings, it shows that it is mostly those that had ever-visited the dentist who reported long queues at the dental facility unlike those who had never been to the dentist. This could be explained by the fact that most participants would go to the dentist when it is too late hence the need for plenty of time for dental treatment per individual. In addition, long queues at the dental facilities are attributed to the big patient provider ratio rather than avoiding HIV patients as noted by some studies [20]. It should be noted that this is a challenge faced by all health facilities and is not exclusive to dental services or groups living with HIV positive patients [121].

According to Table 3a.1 and 3b.1, among the 14-18 and 10-13 age groups, there was no association of cost of dental treatment with ever-use of dental care services. This is contrary to previously conducted studies. A study conducted in North California among adult women living with HIV found that the reason for non-use of dental care services in the previous year by the study participants was associated with low household income less than 6000 U.S dollars [25]. Another study conducted in South Africa among adults living HIV revealed that participants who earned R5,000 or less, were less likely to receive dental care services compared to participants who earned more [122]. The differences could be related to the difference in study populations, age, and locations where the studies were carried out.

In reference to Table 6, participants, 10- to 18-year-olds, who reported failure to get dental treatment because it was not part of the medical appointment were more likely to use dental care services compared to their counterparts who disconfirmed such incoordination. This study findings are similar to a qualitative study carried out among adults living with HIV in Florida [20]. This mentioned study reported that participants got overwhelmed by having to book appointments with both the doctor and the dentist as this caused treatment fatigue [20]. Another study carried out among women living with HIV in Northern California, reported that 21% of the study participants failed to book a dental appointment [25]. However, in the latter

studies, this hindered the use of dental services which is contrary to these study findings. The differences could be attributed to the different study designs and study populations.

In this study, the present findings could be related to the fact that dental care was mainly sought as an emergency treatment for pain; that despite lack of coordination between appointments, participants still used dental care services. The other reason could be stemmed from the fact that HIV itself needs frequent medical care for both check-ups and pick up of ART drugs, unfortunately when oral health needs come into play in an HIV patient it becomes harder to juggle between appointments. In addition, the long queues at the dental facility in combination with the medical appointments scheduled on different days would potentially lead to lost time and hence effect on school attendance for the adolescents and income generating activities to the responsible caregivers and parents as well.

5.4.4 Comparison with other studies reporting on need-related factors associated with use of dental care services

Need related factors associated with ever-use of dental care are presented in Table 4 and 6. According to the multiple variable analysis presented in Table 6, this study found that participants who perceived to have fair overall health of teeth and mouth were less likely to use dental services compared to those who perceived to have a bad overall health of teeth and mouth. This is contradictory to a study carried out among adult women living with HIV in Northern California; that showed that women who had a poor perception of their oral state were less likely to use dental care services [25]. The difference in findings could be related to difference in study populations, study settings, and health financing systems.

From the present study findings, it could be explained that people without any oral problem especially in terms of pain assume to be having a good oral status and thus may not be in need for using dental care services [108].

5.4.5 Comparison with other studies reporting on personal oral hygiene and dental practices associated with use of dental care services

In this study (Table 5), none of the variables under personal oral hygiene and dental practices had an association with ever-use of dental care services. Contrary to our study findings, is a

study carried out adolescents of unknown HIV serostatus in Lesotho that reported adolescents who brushed frequently were more likely to use dental care services [116]. Our study finding is contrary to another study carried out in Burkina Faso among individuals above 15 years of unknown HIV serostatus [49]. In the mentioned study, it was reported that participants who perceived use of fluoride for toothbrushing was important in prevention of tooth decay were more likely to use dental care services [49]. The difference in the findings could be related to difference in study populations, HIV serostatus and geographical locations, hence cannot be comparable to our study findings.

However, previous studies carried out among adults living with HIV on ART in Uganda have reported no association with toothbrushing frequency and use of toothpaste to dental caries [23, 38]. However, these latter studies did not test for association between frequency of tooth brushing and use of dental care services.

The present study findings could be explained that there is a possibility that some dental care providers forget to sensitize patients on oral health education like brushing frequency and use of toothpaste during dental visits. This can be proven by greater numbers of participants that reported they used soap for toothbrushing and were frequent users of dental care services compared to their counterparts who had never-used dental care services as shown in Table 5.

5.4.6 Comparison with other studies reporting on oral health related experiences associated with use of dental care services

In this study (Table 7), extraction or "having teeth pulled" emerged as the main reason for the last dental visit among those that had ever-used dental care services. This finding is similar to a study done in South Africa among children living with HIV where it was reported that majority of the children had extractions for management of dental caries [123]. This study finding is also similar to a Kenyan study carried out among female caregivers of children living with HIV that revealed tooth extraction was the main treatment offered to the children [33].

This kind of result from the present study may be explained by the fact that many individuals are unaware of the various treatment options as well as limited access to preventive treatment options. The other reason would be connected to a certain extent the financial status and

perception of relevance of dental treatment by this category of individuals. This could in turn lead to accessing the dentist when it is too late to get other more cheaper treatment options.

This study also revealed that among those that ever-used dental care services (Table 7), emergency tooth ache was the second reason for the last dental visit. This finding is similar to study carried among children (2-12) living with HIV in South Africa that showed most children only visited the dentist due to discomfort in the mouth rather than check-up [123]. This present study finding may be explained by the fact that dental and mouth pain comes as an emergency with a lot of discomfort and aching, that seeking dental care services presents as the only option for the relief. This result also signifies that use of dental care services in this population and in Uganda is not regular and is done for treatment purposes rather than prevention. This is also confirmed by a small percentage of individuals who visited the dentist for check-up reasons in this study. In general, oral health is given low priority and perceived as being not so important compared with general health therefore dental visits are suspended until one gets tooth ache/ dental and mouth pain that are unbearable.

Dental and mouth pain poorly affects quality of life and dental visits resulting from pain usually aim at emergency pain relief [48].

In addition, among those who had ever-used dental care, cost of dental care cannot be ignored as this study also revealed that cost of dental services determined type of facility participants visited in case of need of dental care services. This sub-study showed that most of those that ever-used dental services sought care from public facilities while more than half used public transport to visit these facilities.

In reference to this, in Uganda, public facilities often offer dental services at very low or no cost at all while public transport is a cheap transport alternative for many Ugandans. Previous studies in Uganda have reported that people of low social economic status in the urban settings were more likely to be infected with HIV [124]. This could further explain a possible bias that cost of dental care services could be a barrier in seeking dental services in a Uganda urban setting like Kampala.

Therefore, the role played by cost in use of dental care cannot be ignored.

5.4.7 Comparison with other studies reporting on HIV-related dental care experiences

In reference to Table 8 of this study, some participants reported that they felt that the dental care services rendered to them were different from their friends and families who did not have HIV. In addition, the same number of participants reported that the dentists treated them poorly when they sought dental care services. There was a participant who withheld his/her HIV status from the dentist before receiving dental treatment. Our study findings are likened to a study carried out among dental patients of both known and unknown HIV serostatus in Khartoum, Sudan [47]. In this Sudanese study, 50.4% of the participants reported they had a negative attitude towards people with HIV infection with main concerns about HIV transmission [47]. Another study with similar findings is the study among adults living with HIV in Florida [20]. In this mentioned study, some participants reported that they faced challenges of finding a dentist to treat them because of their HIV serostatus [20].

These study findings imply that despite education about spread and transmission of HIV, HIV stigma and discrimination remains a challenge among all groups of people living with HIV [125]. This could explain the bad attitude of some of dental care providers towards treating them. Withholding the HIV status from the dentist could be related to the fear of rejection and possible loss of confidentiality because of their medical state. Unfortunately, such negative perceptions and attitudes from dental care providers towards people living with HIV will further deter such groups of people from seeking dental care services they need. However, due to the sample size of this category of participants (n=19), our study findings could not infer any associations but rather provide a basis for further research on HIV-related dental experiences in Uganda.

5.5 Recommendations

This study revealed that study participants were afraid of going to the dentist. This is most likely be due to fear of dental instruments and procedures. Hence this points out a need to promote public health campaigns that raise patient dental awareness, showing availability and usage of various oral health programs and help reduce the fear patients may have about the dental care services [108, 117]. Public health campaigns should also involve sensitization of the importance of good oral health care and its relevance in persons living with HIV. These campaigns should be directed to both the affected groups and general health care practitioners

that are in frequent contact with these patients. There needs to be synchrony between medical and dental appointments among adolescents living with HIV to allow for a comprehensive management plan of these groups of people. In addition, there should be policies focused on education of oral health preventive programs among the general health practitioners and nurses taking care of persons living with HIV. This to enable an understanding of the significance of oral health and influence in the general quality of life of these groups of people.

For the concern of long queues at the dental facility, this challenge can be addressed and overcome by investing in training of more dental practitioners and other oral health cadres like dental hygienists to balance the imbalances in the patient-dentist ratios [126]. Contradictory results concerning effect of demographics on use of dental care services call for more studies in this area to ascertain the true association that exists and thus design interventions that are targeted and are group specific. Evaluation of association between everuse of dental care services and adolescents living with HIV can be carried out using larger sample sizes and other social behavioural models to compare findings and promote effective policies to favour accessibility and use of dental care services.

Additional efforts should be geared towards sensitization of the masses and dental care providers about equal treatment of people living with HIV to combat stigma and discrimination. There should be drivers towards an insurance program in Uganda to support dental costs of people living with HIV to encourage health seeking behaviour and hence offload the unmet need of dental care services.

6.0 Conclusion

The study revealed that the prevalence of ever-use of dental care services was low among the adolescents living with HIV and taking ART that participated in this study. This means that despite the high rate of oral disease in persons with HIV that might result in a high need for dental care services, many do not use dental services regularly. The factors associated with ever-use of dental care services according to enabling factors included fear of the dentist, failure to get dental treatment because it was not part of the medical appointment and long queues at the dental facilities (among those 14-18 years). This reflects that both personal and structural factors such as fear. Organization and financing of the dental care services play an important role when it comes to utilization of dental care services among the vulnerable group of young people investigated. None of the personal oral hygiene practices and the

predisposing factors showed a statistical significance with ever-use of dental care services among the study group, however they were evident differences between groups that cannot be ignored. The findings of this study constitute a step forward when it comes to knowledge about use of dental care services in the younger HIV infected population of Uganda. The findings of this study in addition, establish a foundation for more research among adolescents living with HIV and determinants associated with use of dental care services. It highlights the importance of adequate health systems in oral health promotion and its integration within the HIV medical programs.

7.0 Tables of results

Table 1: Distribution of study variables in total, among 10-18-year-old adolescents

according to gender (n=202)

Variables	Total (n=202)	Male (n=113)	Female (n=89)
Predisposing factors			
Continuous variables Median (IQR)			
Age (years)	13(10-18)	13(10-18)	13(10-18)
Categorical Variables frequency (%)			
Age categories			
10-13	105(52.0)	58(51.3)	47(52.8)
14-18	97(48.0)	55(48.7)	42(47.2)
Education level			
No formal school	11(5.5)	8(7.1)	3(3.4)
Primary level	132 (65.3)	65 (57.5)	67 (75.3)
Secondary level	59 (29.2)	40 (35.4)	19 (21.3)
Socioeconomic status			
Low quintile	122(60.4)	75(66.4)	47(52.8)
High quintile	80(39.6)	38(33.6)	42(47.2)
Home description			
Good	119(58.9)	62(54.9)	57(64.0)
Bad	83(41.1)	51(45.1)	32(36.0)
Ever-use of dental care			
No	177 (87.6)	98 (86.7)	79 (88.8)
Yes	25 (12.4)	15 (13.3)	10 (11.2)
Enabling factors			
Afraid going to dentist			
No	182(90.1)	101(89.4)	81(91.0)
Yes	20(9.9)	12(10.6)	8(9.0)
Knowledge of Dental facility next to			
residence			
No	139(68.8)	78(69.0)	61(68.5)
Yes	63(31.2)	35(31.0)	28(31.5)
Knowledge of Dental facility next to HIV			
Centre			
No	63(31.2)	32(28.3)	31(34.8)
Yes	139(68.8)	81(71.7)	58(65.2)
Failure to get dental treatment because it			
is not part of the medical appointment			
No	194(96.0)	109(96.5)	85(95.5)
Yes	8(4.0)	4(3.5)	4(4.5)
Illness from other conditions			
No	194(96.0)	108(95.6)	86(96.6)
Yes	8(4.0)	5(4.4)	3(3.4)
Avoid dental care due to cost			
No	177(87.6)	100(88.5)	77(86.5)
Yes	25(12.4)	13(11.5)	12(13.5)
Responsible person in decision making			
Parents/caregiver/teacher	181 (89.6)	98 (86.7)	83(93.3)
Myself	21 (10.4)	15 (13.3)	6(6.7)

Table 1 continued: Distribution of study variables in total, among 10-18-year-old

adolescents according to gender (n=202)

Variables	Total (n=202)	Male (n=113)	Female (n=89)
Need related factors			X
Perception about overall general			
health			
Poor	8(4.0)	5(4.4)	3(3.4)
Fair	43 (21.3)	27(23.9)	16(18.0)
Good	151(74.7)	81(71.7)	70(78.6)
Perception about health of teeth			
and mouth			
Bad	20(9.9)	11(9.7)	9(10.1)
Fair	76(37.6)	44(38.9)	32(36.0)
Good	106(52.5)	58(51.3)	48(53.9)
Satisfaction teeth			
Dissatisfied	104(51.5)	57(50.4)	47(52.8)
Satisfied	98(48.5)	56(49.6)	42(47.2)
Need for dental treatment			
No	61 (30.2)	33(29.2)	28(31.5)
Yes	141(69.8)	80(70.8)	61(68.5)
Dental and mouth pain			
No	124(61.4)	72(63.7)	52 (58.4)
Yes	78(38.6)	41(36.3)	37(41.6)
Bleeding gums			
No	158(78.2)	88(77.9)	70(78.6)
Yes	44(21.8)	25(22.1)	19(21.4)
Bad oral odour			
No	167(82.7)	91(80.5)	76(85.4)
Yes	35(17.3)	22(19.5)	13(14.6)
Personal oral hygiene and dental			
practices			
Tooth brushing frequency	07(42.1)	12(27.2)	45(50.0)
Rarely brush	8/(43.1)	42(37.2)	45(50.6)
Daily	115(56.9)	/1(62.8)	44(49.4)
Oral hygiene materials			
Use of soap	195(01 ()	101(00 4)	94(94.4)
NO Vas	185(91.0)	101(89.4) 12(10.6)	84(94.4) 5(5.6)
res Use of calt	1/(8.4)	12(10.6)	5(5.6)
Use oj sau No	150(79.7)	02(92.2)	66(74.2)
NO Vas	139(70.7)	93(82.3)	00(74.2)
ies Use of logal harbs	43(21.5)	20(17.7)	23(23.8)
No	108(08.0)	110(07.4)	88(08 0)
No	198(98.0)	110(97.4) 2(2.6)	1(1, 1)
ICS Use of Ash	4(2.0)	5(2.0)	1(1.1)
No	153(757)	92(81 4)	61(68.5)
Vas	100(74.3)	21(18.6)	28(31.5)
100 Use of Toothnaste	T)(27.3)	21(10.0)	20(31.3)
No	7(3,5)	3(27)	4(4,5)
Ves	195(96 5)	110(97 3)	-(
103	195(90.5)	110(27.3)	05(35.5)

Variable	Ever visited the d	entist		
	Yes n (%)	No n (%)	P value	
Gender				
Male	15(60.0)	98 (55.4)	0.83	
Female	10(40.0)	79 (44.6)		
Age				
10-13	11 (44.0)	94 (53.1)	0.40	
14-18	14(56.0)	83 (46.9)		
Education level				
No formal school	1 (4.0)	10 (5.7)	0.18	
Primary level	13 (52.0)	119 (67.2)		
Secondary level	11 (44.0)	48 (27.1)		
Socio-economic status				
Low quintile	16 (64.0)	106 (59.9)	0.83	
High quintile	9 (36.0)	71 (40.1)		
Home description				
Good	15(60.0)	104 (58.8)	1.00	
Bad	10(40.0)	73 (41.2)		

Table 2: Percentages (n) of adolescents, 10-18 years, confirming ever-use of dental careservices according to predisposing factors. Fisher's exact test, (n=202)

Table 3: Percentages (n) of adolescents, 10-18 years, confirming ever-use of dental careservices according to enabling factors, Fisher's exact test, (n=202)

Variable	Ever visited the dentist		
	Yes n (%)	No n (%)	P- value
Afraid going to dentist			
No	20(80.0)	162 (91.5)	
Yes	5(20.0)	15 (8.5)	0.08
Knowledge of Dental facility next to			
residence			
No	17(68.0)	122 (68.9)	
Yes	8(32.0)	55 (31.1)	1.00
Knowledge of Dental facility next to HIV			
Centre			
No	7(28.0)	56 (31.6)	
Yes	18(72.0)	121 (68.4)	0.82
Failure to get dental treatment because it			
is not part of the medical appointment			
No	20(80.0)	174 (98.3)	
Yes	5(20.0)	3 (1.7)	0.001**
Illness from other conditions			
No	20(80.0)	174 (98.3)	
Yes	5(20.0)	3 (1.7)	0.001**
Avoid dental care due to cost			
No	20(80.0)	157 (88.7)	
Yes	5(20.0)	20 (11.3)	0.21
Responsible person in decision making			
Parents/caregiver/teacher	24 (96.0)	157 (88.7)	0.48
Myself	1 (4.0)	20 (11.3)	

Table 3a. 1: Percentages (n) of adolescents, 14-18 years, confirming ever-use of dentalcare services according to enabling factors. Fisher's exact test, (n=97)

Overall n (%) Yes n (%) No n (%) P-value Dental care costly No 27 (27.8) 7 (50.0) 20 (24.1) Yes 70 (72.2) 7 (50.0) 63 (75.9) 0.06*
Dental care costly 27 (27.8) 7 (50.0) 20 (24.1) Yes 70 (72.2) 7 (50.0) 63 (75.9) 0.06*
No 27 (27.8) 7 (50.0) 20 (24.1) Yes 70 (72.2) 7 (50.0) 63 (75.9) 0.06*
Yes 70 (72.2) 7 (50.0) 63 (75.9) 0.06* Visiting the dentist will
Visiting the dentist will
make me miss school No
Yes $27(27.8)$ $3(21.4)$ $24(28.9)$
70(72.2) 11(78.6) 59(71.1) 0.75
I will not get good care from dental provider No
Yes 35 (36.1) 6 (42.9) 29 (34.9) 0.56
62 (63.9) 8 (57.1) 54 (65.1)
Dental services time consuming
No 26 (26.8) 2 (14.3) 24 (28.9)
Yes 71 (73.2) 12 (85.7) 59 (71.1) 0.34
Long queues at the dental facilities
No 22 (22.7) 0 (0.0) 22 (26.5)
Yes 75 (77.3) 14 (100.0) 61 (73.5) 0.04*
Parents would allow visiting a dentist Yes
No 2 (2.1) 0 (0.0) 2 (2.4) 1.00
95 (97.9) 14 (100.0) 81 (97.6)
Teachers would allow visiting the dentist Yes
No 3 (3.1) 1 (7.1) 2 (2.4)
94 (96.9) 13 (92.9) 81 (97.6) 0.38

NB: At bivariate analysis; **p<0.001, *p<0.05

Table 3b. 1: Percentages (n) of adolescents, 10-13 years, confirming ever-use of dentalcare services according to enabling factors. Fisher's exact test, (n=105)

Variable		Ever visited dentis	t	
	Overall (n%)	Yes n (%)	No n (%)	P-value
Dental services costly				
No				
Yes	21 (20.0)	1 (9.1)	20 (21.3)	
	84 (80.0)	10 (90.9)	74 (78.7)	0.69
Visiting the dentist will				
make me miss school				
No				
Yes	11 (10.5)	0 (0.00)	11 (11.7)	
	94 (89.5)	11 (100.0)	83 (88.3)	0.60
I will not get good care				
from the dental service				
provider				
No				
Yes	40 (38.1)	5 (45.5)	35 (37.2)	
	65 (61.9)	6 (54.5)	59 (62.8)	0.75
Dental services are time	9			
<i>consuming</i>	26(242)	2(27.2)	22(25,1)	
NO Vac	30 (34.3) 60 (65 7)	3 (27.3) 8 (72.7)	33(33.1)	0.75
I es	09 (03.7)	8 (72.7)	01 (04.9)	0.75
dental facilities				
No	25 (23.8)	2 (18.2)	23 (24.5)	
Yes	80 (76.2)	9 (81.8)	71 (75.5)	1.00
Teachers would allow				
visiting the dentist				
No				
Yes	1 (1.0)	1 (9.1)	0 (0.0)	
	104 (99.0)	10 (90.9)	94 (100.0)	0.11

Variable	Ever visited the dentist		P value
	Yes (n/%)	No n (%)	
<i>general health</i> Poor	3 (12.0)	5 (2.8)	
Fair	8 (32.0)	35 (19.8)	
Good	14 (56.0)	137 (77.4)	0.02*
<i>Perception about health of teeth and mouth</i> Bad	9(36.0)	11 (6.2)	
Fair	8(32.0)	68 (38.4)	
Good	8(32.0)	98 (55.4)	0.00**
Satisfaction teeth			
Dissatisfied	19(76.0)	85 (48.0)	
Satisfied	6(24.0)	92 (52.0)	0.01*
Need for dental treatment			
No	5(20.0)	56 (31.6)	
Yes	20(80.0)	121 (68.4)	0.35
Dental and mouth pain			
No	11(44.0)	113 (63.8)	0.08
Yes	14(56.0)	64 (36.2)	
Bleeding gums			
No	18(72.0)	140 (79.1)	0.44
Yes	7(28.0)	37 (20.9)	
Bad oral odour			
No	18(72.0)	149 (84.2)	0.16
Yes	7(28.0)	28 (15.8)	

Table 4: Percentages (n) of adolescents, 10-18 years, confirming ever-use of dental care services according to need related factors. Fisher's exact test (n=202)

NB: At bivariate analysis; **p<0.001, *p<0.05

Table 5: Percentages (n) of adolescents, 10-18 years, confirming ever-use of dental care services according to personal oral hygiene and dental practices, Fisher's exact test, (n=202)

Variable	Ever visited t	he dentist	
	Yes n (%)	No n (%)	P -value
Tooth brushing frequen	ису		
Rarely brush	9(36.0)	78 (44.1)	
Daily	16 (64.0)	99 (55.9)	0.52
Oral hygiene materials			
Use of soap			
No	21(84.0)	164 (92.7)	
Yes	4(16.0)	13 (7.3)	0.23
Use of salt			
No	22(88.0)	137 (77.4)	
Yes	3(12.0)	40 (22.6)	0.30
Use of local herbs			
No	25(100.0)	173 (97.7)	
Yes	0(0.0)	4 (2.3)	1.00
Use of Ash			
No	21(84.0)	132 (74.6)	
Yes	4(16.0)	45 (25.4)	0.45
Use of Toothpaste			
No	1(4.0)	6 (3.4)	
Yes	24(96.0)	171 (96.6)	1.00

Table 6: Predisposing, enabling and need related factors associated with ever-use of dental care services among HIV positive adolescents, 10-18 years. Modified Poisson regression analysis (n=202)

Variable	PR	95%CI	P-value
Predisposing factors			
Gender			
Male	1	1	
Female	0.94	0.55-1.60	0.83
Age			
10-13	1	1	
14-18	1.34	0.71-2.57	0.37
Enabling factors			
Afraid of going to the dentist			
No	1	1	
Yes	2.62	1.04-6.60	0.04
Failure to get dental treatment because it is not part of the			
medical appointment			
No	1	1	
Yes	3.16	2.41-4.16	< 0.001
Illness from other conditions			
No	1	1	
Yes	1.65	0.68-3.98	0.26
Need related factors			
Perception about health of teeth and mouth			
Bad	1	1	
Fair	0.22	0.05-0.98	0.05
Good	0.31	0.08-1.22	0.09
Perception about overall general health			
Bad	1	1	
Fair	1.28	0.36-4.54	0.71
Good	0.81	0.28-2.36	0.70
Satisfaction with teeth condition			
No	1	1	
Yes	0.35	0.08-1.40	0.14
Dental and mouth pain			
No	1	1	
Yes	0.49	0.15-1.54	0.22

PR- Prevalence Ratio CI- Confidence Interval

Pearson Chi-squared goodness of fit = 183.12 at 190 degrees of freedom; p value = 0.63

Pseudo R-squared=0.17
Table 7: Percentage (n) distribution of oral health and related characteristics among 10-18-year-old adolescents who had ever visited a dentist (n=25)

Variable	Frequency n (%)
Reason for the last dental visit	
Mandatory school check up	
No	24 (96.0)
Yes	1 (4.0)
Emergency toothache	
No	11 (44.0)
Yes	14 (56.0)
Having teeth pulled (tooth extraction)	
No	4 (16.0)
Yes	21 (84.0)
Filling	
No	21 (84.0)
Yes	4 (16.0)
Root canal	. (1000)
No	24 (96 0)
Yes	1(40)
Others	1 (10)
No	24 (96 0)
Ves	1(40)
I ast dontal visit	1 (4.0)
Lass then 1 year	17 (68 0)
More than 1 year but loss than 2 years	6(24.0)
More than 2 years	0(24.0)
Site of dontal comises	2 (8.0)
Sue of aenial services	10 (10)
Private	10 (40)
Public	15 (60)
Means of transport to the dental facility	(210)
Walking	6 (24.0)
Bus/taxi	13 (52.0)
Bicycle	2 (8.0)
Motorcycle	4 (16.0)
Time at the dental facility	
Less than 1 hour	3 (12.0)
Between 1 hour to 2 hours	5 (20.0)
More than 3 hours	17 (68.0)
Travel cost to the dental facility	
No money spent	3 (12.0)
Less than Ug. Sh. 4,000	4 (16.0)
Between Ug. Sh. 4100 – 10000	10 (40.0)
More than 10000	8 (32.0)
Did you feel the dental team listened well and gave you time t	0
explain your problem?	
No	4 (16.0)
Yes	21 (84.0)
Perception of attitude of oral health service providers	
Poor	
Fair	3 (12.0)
Good	2 (8.0)
	20 (80.0)
Awareness of HIV serostatus	- \
No	6 (24.0)
Vac	19 (76 0)

Table 8: Percentage (n) distribution of HIV-related dental care experiences foradolescents, 10-18-year-old who had ever visited the dentist and were aware of their HIVserostatus (n=19)

Variable	Frequency (%)
	19 (100)
Has the dentist ever asked your HIV serostatus before	
offering dental treatment?	
No	14 (73.7)
Yes	5 (26.3)
Have you ever hidden/withheld your HIV status from the	
dentist before receiving dental treatment?	
No	18 (94.7)
Yes	1 (5.3)
Have you ever felt not satisfied with the dental care you	
received because of your HIV status?	
No	17 (89.5)
Yes	2 (10.5)
Have you ever felt the dental care rendered to you was	
different from your friends and family whom you think do	
not have HIV?	
No	16 (84.2)
Yes	3 (15.8)
In general, how would you describe the way your dentist	
treated you?	
Poor	3 (15.8)
Average	4 (21.0)
Good	12 (63.2)

8.0 References

- 1. Ritchie, M.R.a.H., *HIV/AIDS*. Our World In Data, 2018. 2023(10-March-2023).
- 2. UNAIDS. *Young People and HIV*. [Internet] 2021; 1-20]. Available from: <u>https://www.unaids.org/en/resources/documents/2021/young-people-and-hiv</u>.
- 3. UNICEF, *HIV and AIDS in adolescents*. 2021.
- 4. Bekker, L.G., et al., *Building our youth for the future*. J Int AIDS Soc, 2015. **18**(2 Suppl 1): p. 20027.
- 5. UNAIDS. UNAIDS Data 2022. [Internet] 2022 [cited 2023 27th March 2023]; Available from: https://www.unaids.org/en/resources/documents/2023/2022. unaids.data

https://www.unaids.org/en/resources/documents/2023/2022_unaids_data.

- Africa, U.E.a.S. *HIV and AIDS* UNICEF is responding to the HIV epidemic, together with governments and partners, to achieve an AIDS-free generation. [Internet] 2018 [cited 2022 22-June-2022]; Available from: <u>https://www.unicef.org/esa/hiv-and-aids</u>.
- UNICEF. Children and AIDS: Statistical Update. [Internet] 2017 [cited 2022 4-July-2022]; Available from: <u>https://data.unicef.org/wp-content/uploads/2017/11/HIVAIDS-Statistical-Update-2017.pdf</u>.
- 8. Health, M.o., Uganda Population-Based HIV Impact Assessment. UPHIA 2016–2017, 2017.
- 9. Commission, U.A., *HIV Investment Case Framework 2021-30*, in *Investing Now To Save For The Future*. 2021.
- 10. Authority, K.C.C., 2021 Kampala HIV Fact Sheet. 2021: p. 3.
- 11. Ministry of Health, U.P.B.H.I.A., *Release Of Preliminary Results Of The 2020* Uganda Population-Based HIV Impact Assessment 2022: Uganda Media Center.
- 12. Health, M.o., National Antiretroviral Treatment and Care Guidelines for Adults, Adolescents, and Children 2008.
- Phelan, J.A., *Dental lesions: diagnosis and treatment*. Oral Dis, 1997. 3 Suppl 1: p. S235-7.
- 14. Coogan, M.M., J. Greenspan, and S.J. Challacombe, *Oral lesions in infection with human immunodeficiency virus*. Bull World Health Organ, 2005. **83**(9): p. 700-6.
- Reznik, D.A., Oral manifestations of HIV disease. Top HIV Med, 2005. 13(5): p. 143 8.
- Lauritano, D., et al., Oral Manifestations in HIV-Positive Children: A Systematic Review. Pathogens (Basel, Switzerland), 2020. 9(2): p. 88.

- Mohamed, N., et al., Association among oral symptoms, oral health-related quality of life, and health-related quality of life in a sample of adults living with HIV/AIDS in Malaysia. BMC Oral Health, 2017. 17(1): p. 119.
- Janakiram, C., B. Antony, and J. Joseph, Association of Undernutrition and Early Childhood Dental Caries. Indian pediatrics, 2018. 55(8): p. 683-685.
- Gebru, T.H., H.H. Mekonen, and K.G. Kiros, Undernutrition and associated factors among adult HIV/AIDS patients receiving antiretroviral therapy in eastern zone of Tigray, Northern Ethiopia: a cross-sectional study. Arch Public Health, 2020. 78: p. 100.
- 20. Carrigan Parish, K.S., Margaret Pereyra, Terri Liguori and Lisa Metsch, *Barriers and facilitators to dental care among HIV-Infected adults*. Spec Care Dentist., 2015. 35(6): p. 294-302.
- Heslin, K.C., et al., A comparison of unmet needs for dental and medical care among persons with HIV infection receiving care in the United States. J Public Health Dent, 2001. 61(1): p. 14-21.
- 22. Carr, W. and S. Wolfe, *Unmet needs as sociomedical indicators*. Int. J. Health Sci, 1976. **6**(3): p. 417-430.
- 23. Kalanzi, D., et al., Prevalence and factors associated with dental caries in patients attending an HIV care clinic in Uganda: a cross sectional study. BMC Oral Health, 2019. 19(1): p. 159.
- 24. Kutesa, A., et al., *Prevalence and factors associated with dental caries among children and adults in selected districts in Uganda*. Afr Health Sci, 2015. **15**(4): p. 1302-7.
- 25. Shiboski, C.H., et al., *Dental care access and use among HIV-infected women*. Am J Public Health, 1999. **89**(6): p. 834-9.
- Marcus, M., et al., Perceived unmet need for oral treatment among a national population of HIV-positive medical patients: social and clinical correlates. Am J Public Health, 2000. 90(7): p. 1059-63.
- 27. Fox, J.E., et al., Increasing access to oral health care for people living with HIV/AIDS in the U.S.: baseline evaluation results of the Innovations in Oral Health Care Initiative. Public Health Rep, 2012. **127 Suppl 2**: p. 5-16.
- Patton, L.L., et al., Perceived oral health status, unmet needs, and barriers to dental care among HIV/AIDS patients in a North Carolina cohort: impacts of race. J Public Health Dent, 2003. 63(2): p. 86-91.

- Jeanty, Y., et al., Correlates of unmet dental care need among HIV-positive people since being diagnosed with HIV. Public Health Rep, 2012. 127 Suppl 2(Suppl 2): p. 17-24.
- 30. McCarthy, G.M., F.S. Haji, and I.D. Mackie, *Attitudes and behavior of HIV-infected patients concerning dental care*. J Can Dent Assoc, 1996. **62**(1): p. 63-9.
- 31. Pereyra, M., et al., *Utilization of dental care services among low-income HIV-positive persons receiving primary care in South Florida*. AIDS care, 2011. **23**(1): p. 98-106.
- 32. Olorato P. Mathiba, N.M., Riaan Mulder An Oral Health Survey among HIV-infected children younger than twelve years of age presenting at the Paediatric Infectious Diseases Clinic at Tygerberg Hospital. 2017.
- 33. Masiga, M.A., *<Determinants of the Utilization of Oral Healthcare Among Female Caregivers of Children With Hiv-aids in Nairobi City County, Kenya.pdf>.* 2017.
- Rwenyonyi, C.M., et al., Oral Manifestations in HIV/AIDS-Infected Children. Eur. J. Dent, 2011. 5(3): p. 291-298.
- Ramirez-Amador, V., et al., *The Changing Clinical Spectrum of Human Immunodeficiency Virus (HIV)-Related Oral Lesions in 1,000 Consecutive Patients: A 12-Year Study in a Referral Center in Mexico*. Medicine (Baltimore), 2003. 82(1): p. 39-50.
- Mark Chichocki, R. How HAART (Highly Active Antiretroviral Therapy) Works.
 [Internet] [cited 2021 22/11/2021]; Available from: https://www.verywellhealth.com/haart-highly-active-antiretroviral-therapy-48967.
- 37. Scully, C. and P. Diz Dios, *Orofacial effects of antiretroviral therapies*. Oral Dis, 2001. **7**(4): p. 205-10.
- Arubaku, W., et al., Prevalence, correlates and treatment needs of dental caries among people on antiretroviral therapy in Uganda: a cross sectional study. BMC Oral Health, 2022. 22(1): p. 231.
- Andersen, R.M., Revisiting the behavioral model and access to medical care: does it matter? J Health Soc Behav, 1995: p. 1-10.
- 40. Baker, S.R., Applying Andersen's behavioural model to oral health: what are the contextual factors shaping perceived oral health outcomes? Community Dent Oral Epidemiol, 2009. **37**(6): p. 485-94.
- Rocha-Buelvas, A.I., A. Hidalgo Troya, and À. Hidalgo Eraso, Barriers of access to oral health care among university students in southern Colombia, 2011. A multivariate analysis. Rev Fac Med Univ Nac Colomb, 2015. 62(4): p. 521-528.

- 42. Gulcan, F., et al., *Exploring the association of dental care utilization with oral impacts on daily performances (OIDP) - a prospective study of ageing people in Norway and Sweden*. Acta Odontol Scand, 2018. **76**(1): p. 21-29.
- 43. Drachev, S., et al., *Prevalence of and factors associated with dental service utilization among early elderly in Lithuania.* BMC Health Services Research, 2022. **22**.
- 44. Al Agili, D.E. and N.J. Farsi, *Need for dental care drives utilisation of dental services among children in Saudi Arabia.* Int. Dent. J, 2020. **70**(3): p. 183-192.
- 45. Melo, E.A., et al., *Indicators for dental appointment scheduling in primary health care: a national cross-sectional study.* BMC Public Health, 2021. **21**(1): p. 2234.
- 46. Qingping Yun, M.L., Mei Zhao, Lina Yang, Jiangxia Miao, Chun Chang, The willingness to attend the first dental visit within 1 year of age: An analysis applying Andersen's behavioral model of health service utilization. Int. J. Paediatr. Dent, 2021. 32(1).
- 47. Nasir, E.F., et al., Utilization of dental health care services in context of the HIV epidemic- a cross-sectional study of dental patients in the Sudan. BMC Oral Health, 2009. 9(1): p. 30.
- Adeniyi, A.A. and A. Oyapero, *Predisposing, enabling and need factors influencing dental service utilization among a sample of adult Nigerians*. Population Medicine, 2020. 2(December): p. 1-9.
- 49. Varenne, B., et al., Illness-related behaviour and utilization of oral health services among adult city-dwellers in Burkina Faso: evidence from a household survey. BMC Health Services Research, 2006. 6(1): p. 164.
- 50. GwenguP, P., Determinants of Utilization of Oral Health Services by Postnatal Mothers in Winterveldt, Gauteng Province, South Africa. J. oral hyg. health 2017.
- Hajek, A., B. Kretzler, and H.H. König, *Factors Associated with Dental Service Use* Based on the Andersen Model: A Systematic Review. Int J Environ Res Public Health, 2021. 18(5).
- Hajek, A., B. Kretzler, and H.H. König, Determinants of Healthcare Use Based on the Andersen Model: A Systematic Review of Longitudinal Studies. Healthcare (Basel), 2021. 9(10).
- 53. Heron, S.E. and S. Elahi, *HIV Infection and Compromised Mucosal Immunity: Oral Manifestations and Systemic Inflammation.* Front Immunol, 2017. **8**: p. 241.

- 54. Organization, W.H., *Policy brief: HIV prevention, diagnosis, treatment and care for key populations: Consolidated guidelines July 2014.* 2014, World Health Organization.
- 55. Birungi, N., et al., *The prevalence and socio-behavioural and clinical covariates of oral health related quality of life in Ugandan mothers with and without HIV-1*. Health Qual. Life Outcomes, 2021. **19**(1): p. 201.
- 56. Birungi, N., et al., Caries experience by socio-behavioural characteristics in HIV-1infected and uninfected Ugandan mothers – a multilevel analysis. Acta Odontol Scand, 2021: p. 1-8.
- 57. Nabbanja, J., et al., Orofacial manifestations in HIV positive children attending Mildmay Clinic in Uganda. Odontology, 2013. **101**(1): p. 116-120.
- 58. Birungi, N., et al., *Caretaker's caries experience and its association with early childhood caries and children's oral health-related quality of life: A prospective two-generation study.* Acta Odontol Scand, 2016. **74**(8): p. 605-612.
- 59. Nations, U. *Department of Economic and Social Affairs* Sustainable Development [Internet] [cited 2023 10th May 2023]; Available from: <u>https://sdgs.un.org/goals</u>.
- 60. Encyclopaedia, T.E.o. *Kampala*. [Internet] 2021 [cited 2023 18th January 2023]; Available from: <u>https://www.britannica.com/place/Kampala</u>.
- 61. Authority, K.C.C. *Kampala Capital City Authority*. The Authority [Internet] [cited 2023 18th January 2023]; Available from: <u>https://www.kcca.go.ug/about-the-authority</u>.
- 62. Program, M.U.J.A. *Providing Comprehensive HIV Care since 2004*. [Internet] 2004 [cited 2023 11th May 2023]; Available from: <u>https://mjap.mak.ac.ug/</u>.
- 63. Kiggundu, T., et al., Prevalence of microalbuminuria and associated factors among HIV infected ART naive patients at Mulago hospital: a cross-sectional study in Uganda. BMC Nephrol, 2020. 21(1): p. 440.
- 64. VYMaps.com. *Kawaala Health Center*. [Internet] 2023 [cited 2023 11th May 2023]; Available from: <u>https://vymaps.com/UG/Kawaala-Health-Center-55034/</u>.
- 65. Nangendo, J., et al., *Diagnostic accuracy and acceptability of rapid HIV oral testing among adults attending an urban public health facility in Kampala, Uganda.* PLOS ONE, 2017. **12**: p. e0182050.
- 66. VYMaps.com. *Kiswa Health Center*. [Internet] 2023 [cited 2023 11th May 2023]; Available from: <u>https://vymaps.com/UG/kiswa-Health-center-209103375827492/</u>.

- 67. Calculator.net. *Sample size calculator*. [Internet] [cited 2021 26/02/2022]; Available from: <u>https://www.calculator.net/sample-size-calculator.html?type=1&cl=95&ci=5&pp=50&ps=400&x=44&y=19</u>.
- Frost, J. Statistics By Jim: making statistics intuitive. Cluster Sampling: Definitions, Advantages & Examples [Internet] 2021 [cited 2023 28th March 2023]; Available from: <u>https://statisticsbyjim.com/basics/cluster-sampling/</u>.
- 69. ODK. *Collect data anywhere*. [Internet] 2023 [cited 2023 11th May 2023]; Available from: <u>https://getodk.org/</u>.
- Initiative, G.E. *Open Data Kit (ODK)*. Evaluation Tools and Resources [Internet] 2022
 [cited 2023 31st March 2023]; Available from: <u>https://www.betterevaluation.org/tools-resources/open-data-kit-odk</u>.
- 71. Carl Hartung, Y.A., Waylon Brunette, Adam Lerer, Clint Tseng, Gaetano Borriello, *Open Data Kit: Tools to Build Information Services for Developing Regions*. 2010.
- 72. Technology, U.N.C.f.S.a. *Conduct of research during Coronavirus Disease* 2019(COVID-19) Pandemic. [Internet] 2020 [cited 2021 22 December 2021]; Available from:

https://www.unhro.org.ug/assets/images/resources/covidnationalguidelines.pdf.

- 73. Filmer, D. and L.H. Pritchett, *Estimating wealth effects without expenditure data--or tears: an application to educational enrollments in states of India*. Demography, 2001.
 38(1): p. 115-32.
- 74. StataNordic. Welcome to Stata Nordic and Stata 17. [Internet]; Available from: https://www.statanordic.com/?gclid=Cj0KCQjwpv2TBhDoARIsALBnVnkZ4N8Na0c mMbzArVra_huGkl-MAfmgDLWtRZNfBFEIZBIA8dcFXI8aAiE1EALw_wcB.
- 75. Weisstein, E.W. *Fisher's Exact Test*. [Internet] 2022 [cited 2022 28-June-2022]; Available from: <u>https://mathworld.wolfram.com/FishersExactTest.html</u>.
- 76. Kim, H.Y., *Statistical notes for clinical researchers: Chi-squared test and Fisher's exact test.* Restor Dent Endod, 2017. **42**(2): p. 152-155.
- 77. Bower, K.M., When To Use Fisher's Exact Test. 2003.
- 78. Turney, S. Chi-Square (X²) Tests | Types, Formula & Examples. [Internet] 2022 [cited 2023 22nd April 2023]; Available from: <u>https://www.scribbr.com/citation/generator/folders/56PzKh6bIsd6BcGE5S1FU0/lists/</u> evQFQQZr8e6KFK0ohpuzL/sources/493ycb8aTey3BMU5XCjVIo/edit/.

- Kong, O.T.f.H. Strengths and Weaknesses of Quantitative Interviews. [Internet] 2016
 [cited 2023 09 January 2023]; Available from: https://www.opentextbooks.org.hk/ditatopic/29797.
- Azad, A., et al., Conducting In-Depth Interviews via Mobile Phone with Persons with Common Mental Disorders and Multimorbidity: The Challenges and Advantages as Experienced by Participants and Researchers. Int J Environ Res Public Health, 2021. 18(22).
- 81. Thriemer, K., et al., *Replacing paper data collection forms with electronic data entry in the field: findings from a study of community-acquired bloodstream infections in Pemba, Zanzibar.* BMC research notes, 2012. **5**(1): p. 1-7.
- 82. Thomas, L. Cross-sectional studies/ Definitions, Uses and Examples. Research methodology [Internet] 2022 5th May 2022 [cited 2023 16th January 2023]; Available from: https://www.scribbr.co.uk/research-methods/cross-sectional-design/.
- 83. Greenland, S., *Interpretation and choice of effect measures in epidemiologic analyses*.
 Am. J. Epidemiol, 1987. 125(5): p. 761-768.
- 84. Chen, W., et al., Comparing performance between log-binomial and robust Poisson regression models for estimating risk ratios under model misspecification. BMC Medical Research Methodology, 2018. 18(1): p. 63.
- 85. Travers, J.L., K.B. Hirschman, and M.D. Naylor, *Adapting Andersen's expanded* behavioral model of health services use to include older adults receiving long-term services and supports. BMC Geriatrics, 2020. **20**(1): p. 58.
- Hahm, H.C., A.E. Speliotis, and S.S. Bachman, *Failure to receive health care among people with mental illness: theory and implications*. J Soc Work Disabil Rehabil, 2008. 7(2): p. 94-114.
- 87. Babitsch, B., D. Gohl, and T. von Lengerke, *Re-revisiting Andersen's Behavioral Model of Health Services Use: a systematic review of studies from 1998-2011.*Psycho-social medicine, 2012. 9: p. Doc11-Doc11.
- 88. LaMorte, W.W. *The Theory Of Planned Behavior*. Behavioral Change Models [Internet] 2022 3rd November 2022 [cited 2023 16th January 2023]; Available from: <u>https://sphweb.bumc.bu.edu/otlt/mph-</u>

modules/sb/behavioralchangetheories/BehavioralChangeTheories3.html.

LaMorte, W.W. *The Health Belief Model*. Behavioral Change Models [Internet] 2022
 3rd November 2022 [cited 2023 16th January 2023]; Available from:

https://sphweb.bumc.bu.edu/otlt/mphmodules/sb/behavioralchangetheories/Behavioral ChangeTheories2.html.

- 90. Tripepi, G., et al., *Selection Bias and Information Bias in Clinical Research*. Nephron Clin. Pract, 2010. **115**(2): p. c94-c99.
- 91. Gay, J. *Epidemiology: Validity*. [Medium] Oct 25, 2022 7-Nov-2022]; Available from: <u>https://pct.libguides.com/epidemiology/clinical-</u> <u>research/validity#:~:text=Internal%20Validity&text=A%20study%20is%20internally</u> <u>%20valid,execution%2C%20and%20analysis%20were%20correct</u>.
- 92. Althubaiti, A., *Information bias in health research: definition, pitfalls, and adjustment methods.* J Multidiscip Healthc, 2016. **9**: p. 211-7.
- 93. Columb, M. and M. Atkinson, *Statistical analysis: sample size and power estimations*.BJA Education, 2015. 16(5): p. 159-161.
- 94. Precision, P.A. What Is Power Analysis? : Precision Analysis. Find the sample size you need.....FAST [Internet] 2000 [cited 2023 24th April 2023]; Available from: <u>https://www.power-</u> analysis.com/precision_sample_size.htm#:~:text=The%20confidence%20interval%20r epresents%20the,factor%20in%20determining%20the%20precision.
- 95. Myers, J. Introductory Epidemiology. EPI8-1: The Quality Of Measurements: Precision Or Random Variation And Bias Or Systematic Variation [Internet] [cited 2023 11th April 2023]; Available from: https://vula.uct.ac.za/access/content/group/9c29ba04-b1ee-49b9-8c85-9a468b556ce2/DOH/Module%202%20(Bio_Epi)/Epidemiology/EPIDEMIOLOGY/Pr ecise/EPI8-1.htm.
- 96. Middleton, F. Reliability Vs. Validity in Research/ Differences, Types and Examples. [Internet] 2023 [cited 2023 11th April 2023]; Available from: https://www.scribbr.com/methodology/reliability-vsvalidity/#:~:text=Reliability%20can%20be%20estimated%20by,other%20relevant%2 Odata%20or%20theory.
- 97. KJ, R., *Epidemiology*. An Introduction. 2002, New York: Oxford University Press.
- 98. UNICEF. Monitoring the situation of children and women. UNICEF Data Warehouse, Estimated number of new HIV infections (10-19) [Internet] 2000-2020 [cited 2022 4-July 2022]; Available from: <u>http://aidsinfo.unaids.org/</u>.

- 99. Shrank, W.H., A.R. Patrick, and M.A. Brookhart, *Healthy user and related biases in observational studies of preventive interventions: a primer for physicians*. J Gen Intern Med, 2011. 26(5): p. 546-50.
- 100. Chen, F., Y. Cheng, and T. Xie, *Oral Health Status of Young People Infected with HIV in High Epidemic Area of China.* J Multidiscip Healthc, 2021. **14**: p. 831-837.
- Cheng, Y., et al., Effectiveness of a school-based AIDS education program among rural students in HIV high epidemic area of China. J Adolesc Health, 2008. 42(2): p. 184-91.
- 102. (FDI), W.D.F. How China Is Facing The Future Oral Health For The FDI World Dental Congress 2020 In Shanghai. [Internet] 2019 18th October 2019 [cited 2023 12th April 2023]; Available from: <u>https://www.fdiworlddental.org/how-china-shaping-future-oral-health-fdi-world-dental-congress-2020-shanghai</u>.
- 103. Twaha, A., Uganda hit by dentists' shortage, in Monitor. 2018.
- 104. Bank, T.W. World Bank Country Classifications By Income Level (Uganda). [Internet] 2022 7th July 2022 [cited 2023 12th April 2023]; Available from: https://www.worldbank.org/en/news/factsheet/2022/07/07/world-bank-countryclassifications-by-income-leveluganda#:~:text=Q8%3A%20What%20is%20the%20current,issued%20on%20July%2 01%2C%202022.
- 105.Bank, T.W. The World Bank In China. [Internet] 2023 11th April 2023 [cited 202312thApril2023];Availablefrom:https://www.worldbank.org/en/country/china/overview.
- 106. Adedigba, M.A., et al., *Pattern of Utilisation of Dental Health Care Among HIVpositive Adult Nigerians.* Oral Health Prev Dent, 2016. **14**(3): p. 215-25.
- 107. Febronia Kokulengya Kahabuka, P.E.P., Hawa Shariff Mbawala, Nanna Jürgensen, General and Oral Health Related Behaviors among HIV Positive and the Background Adult Tanzanian Population. J. oral hyg. health, 2014. 2:162.
- 108. Ofili, D.C., E.B. Esu, and R.I. Ejemot-Nwadiaro, Oral hygiene practices and utilization of oral healthcare services among in-school adolescents in Calabar, Cross River State, Nigeria. Pan Afr Med J, 2020. 36: p. 300.
- Okullo, I., A.N. Astrom, and O. Haugejorden, Social inequalities in oral health and in use of oral health care services among adolescents in Uganda. Int J Paediatr Dent, 2004. 14(5): p. 326-35.

- 110. Chaudhary, P., et al., Oral health status and treatment needs among HIV/AIDS patients attending antiretroviral therapy center in Western India: A cross-sectional study. J Family Med Prim Care, 2020. 9(7): p. 3722-3728.
- 111. Bajomo, A.S., et al., Impact of oral lesions among South African adults with HIV/AIDS on oral health-related quality of life. J. Dent. Sci, 2013. **8**(4): p. 412-417.
- 112. Malele Kolisa, Y., et al., *The burden of oral conditions among adolescents living with HIV at a clinic in Johannesburg, South Africa.* PLoS One, 2019. **14**(10): p. e0222568.
- 113. Kwagala, D.T., 60 years of private dental practice: what we so far?, in The Observer.2022: Observer Media Limited.
- 114. Mwesigwa, C.L., et al., *Mapping the geographic availability of public dental services in Uganda relative to ruralization and poverty of the population*. J. glob. oral health, 2020. 2: p. 86-92.
- 115. Tobias, C.R., et al., *Retention of people living with HIV/AIDS in oral health care*.Public Health Rep, 2012. **127 Suppl 2**(Suppl 2): p. 45-54.
- 116. Abbas Jessani, F.Q., Abdul El-Rabbany, Kirsten Hooper, Hyun Ja Lim, Eketsang Ndobe, Mario Brondani, Denise Laronde, Oral Health Status and Patterns of Dental Service Utilization of Adolescents in Lesotho, Southern Africa. 2020.
- 117. Shiboski, C.H., et al., *Factors associated with use of dental services among HIVinfected and high-risk uninfected women.* J Am Dent Assoc, 2005. **136**(9): p. 1242-55.
- 118. Chakradhar, K., et al., Correlation of dental anxiety with oral health status and treatment needs among 12-year old indian school going children. Acta Biomed, 2020.
 91(4): p. e2020095.
- Balemwa, N.D., Utilization of oral health services and barriers among HIV patients visiting public and private health facilities in Kampala Capital City, Uganda. 2018, Makerere University.
- 120. Yildirim, T.T., *Evaluating the Relationship of Dental Fear with Dental Health Status and Awareness.* J Clin Diagn Res, 2016. **10**(7): p. Zc105-9.
- 121. Oche, M. and H. Adamu, Determinants of patient waiting time in the general outpatient department of a tertiary health institution in north Western Nigeria. Ann Med Health Sci Res, 2013. 3(4): p. 588-92.
- 122. Naidoo, M.T.a.S., Oral health care experiences of peopleliving with HIV in Kwazulu-Natal and Western Cape, South Africa. Int. J. Hum. Rights Healthc, 2015. 8(2): p. 59-69.

- 123. Mohamed, N., O.P. Mathiba, and R. Mulder, Oral status of HIV-infected children aged 12 years or younger who attended a Paediatric Infectious Diseases Clinic in Cape Town. Clin Exp Dent Res, 2020. 6(1): p. 75-81.
- 124. Igulot, P. and M.A. Magadi, Socioeconomic Status and Vulnerability to HIV Infection in Uganda: Evidence from Multilevel Modelling of AIDS Indicator Survey Data. AIDS Res Treat, 2018. 2018: p. 7812146.
- 125. Prevention, C.f.D.C.a. HIV Stigma And Discrimination. [Internet] 2021 1st June 2021 [cited 2023 24th April 2023]; Available from: <u>https://www.cdc.gov/hiv/basics/hiv-stigma/index.html</u>.
- 126. Jones, J., et al., *Increasing access to oral health care for people living with HIV/AIDS in rural Oregon*. Public Health Rep, 2012. **127 Suppl 2**(Suppl 2): p. 65-72.

9.0 Appendix A Quantitative questionnaire about factors influencing and barriers to access of dental care

Biodata

ID

Introductory questions for caregivers

- 1. Does the child/adolescent know their HIV status?
 - 1. Yes
 - 0. No
 - 3. Phone owner is child/adolescent
- 2. Is the caregiver/parent present?
 - 1. Yes
 - 0. No
- 3. Have you ever taken your child to a dentist in your lifetime?
- 1. Yes
- 0. No
 - 4. What influenced you to choose where you went for treatment? Choose the most appropriate choice
 - a) distance from home
 - 1. agree completely
 - 2. agree partly
 - 3. disagree partly

- 4. disagree completely
- 5. I do not know
- b) cost of treatment
 - 1. agree completely
 - 2. agree partly
 - 3. disagree partly
 - 4. disagree completely
 - 5. I do not know
- c) comfort/accommodation
- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know
- d) attitude of the health workers
- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know
- e) convenient opening and closing hours of the facility
- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know

- f) same as health centre where medication is received/close by
- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know
- g) recommended by a friend/any person
- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know

Introductory questions for adolescents

NB: Please record audio agreeing to assent or consent

Factors influencing and barriers to access of dental care

Initial of assessor:

Biodata

Gender

- 0. male
- 1. female

Age

Which class are you?

- 1. Primary 1-3
- 2. Primary 4-7
- 3. Senior 1-4
- 4. Senior 5 or 6
- 5. Vocational courses
- 6. Not attending school

Do the health workers in your health facility..... look into your mouth when you go for the visits?

- 0. Never
- 1. Rarely
- 2. Frequently
- 3. Always/on every visit

Would you want these health workers to give you advice about your teeth and mouth?

- 0. No, it is not their part or their work
- 1. I do not know if the mouth and teeth concern them
- 2. Yes, it would be helpful

Predisposing factors (socio-demographic characteristics)

Do you have any of the following things in your home and do they work?

- 1. Television
- 2. Electricity
- 3. Bicycle
- 4. water
- 5. Motor car
- 6. Flush toilet
- 7. Mobile phone
- 8. Computer

- 9. Radio
- 10. motorcycle
- 11. Refrigerator

Are your caregivers/parents renting?

- 1. Yes
- 0. No

How many rooms does your house have?

- 1. single room
- 2. double rooms
- 3. more than 2 rooms

How many people sleep in the main house?

- 4. I stay alone
- 3. we are 2 people at home
- 2. we are 3-5 people at home
- 1. we are more than 5 people at home

How would you describe your home?

- 1. very good
- 2. good
- 3. bad
- 4. very bad
- 5. I do not know

Enabling resources

Do you fear going to the dentist?

- 1. I do not fear
- 2. I fear a little
- 3. Very fearful

Do you know of any dental facility near your home?

- 1. Yes
- 0. No

Do you know of any dental facility near where you normally go for health care.....?

- 1. Yes
- 0. No

Do you know of any dental facility near where you receive your HIV care?

- 1. Yes
- 0. No

Have you avoided dental care due to your HIV status?

- 1. yes, several times
- 2. yes, a few times
- 3. no, never
- 4. I do not know

Have you avoided dental care due to fear of spread of HIV?

- 1. yes, several times
- 2. yes, a few times
- 3. no, never
- 4. I do not know

Have you failed to get dental treatment because it isn't part of your medical appointment?

- 1. yes, several times
- 2. yes, a few times
- 3. no, never
- 4. I do not know

Have you avoided dental care because of illness from other medical conditions?

- 1. yes, several times
- 2. yes, a few times
- 3. no, never
- 4. I do not know

Have you avoided dental care due to cost?

- 1. yes, several times
- 2. yes, a few times
- 3. no, never
- 4. I do not know

Who decides whether you are to see a dentist or not if you have pain in your teeth or mouth?

- 1. my parents
- 2. myself
- 3. my caregiver
- 4. my teacher
- 5. I do not know

Enabling resource's part 2 for children above 14 years

Please choose the most appropriate response to the following statements

If I go to the dentist when I have problems with my teeth or mouth.

Please agree or disagree to the following statement

It will cost me a lot of money

- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know

I will miss school

- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know

I will not get good care

- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know

It will take me a lot of time

- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. do not know

The waiting lines will be long

- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know

My parents will allow me to go to the dentist when I have problems with my teeth or mouth

- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know

My teacher will allow me to go to the dentist when I have problems with my teeth or mouth

- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know

Going to a dentist when in need of dental care is good for health

- 1. agree completely
- 2. agree partly
- 3. disagree part
- 4. disagree completely
- 5. I do not know

Going to a dentist a dentist when in need of dental care is useful

- 1. agree completely
- 2. agree partly
- 3. disagree partly
- 4. disagree completely
- 5. I do not know

Enabling factors part 3 for children below 14 years

Please choose the most appropriate response to the following statements If I go to the dentist when I have problems with my teeth or mouth. Please answer yes or no to the following statements

It will cost me a lot of money

- 1 yes
- 0 No
- 3 I do not know

I will miss school

- 1 yes
- 0 No
- 3 I do not know

I will not get the attention I need

- 1 yes
- 0 No
- 3 I do not know

It will take me a lot of time

- 1 Yes
- 0 No
- 3 I do not know

The waiting lines will be long

- 1 yes
- 0 No
- 3 I do not know

My parents will allow me to go to the dentist when I have problems with my teeth or mouth

- 1 yes
- 0 No
- 3 I do not know

My teacher will allow me to go to the dentist when I have problems with my teeth or mouth

- 1 yes
- 0 No
- 3 I do not know

Going to a dentist when in need of dental care is good for health

- 1 yes
- 0 No
- 3 I do not know

Going to a dentist a dentist when in need of dental care is useful

- 1 yes
- 0 No
- 3 I do not know

Need related factors

How would you rate your health in general?

- 5 excellent
- 4 very good
- 3 good
- 2 fair/average
- 1 poor

In general, how would you rate the health of your teeth and mouth?

- 1 excellent
- 2 very good
- 3 good
- 4 fair
- 5 bad

Are you satisfied/ happy with the health of your teeth or mouth?

- 1 very satisfied
- 2 satisfied
- 3 dissatisfied
- 4 very dissatisfied

Do you think/feel you need dental treatment?

- 1 yes
- 0 No
- 3 I do not know

Do you have pain because of your teeth or mouth?

- 1 yes
- 0 No

Do you have bleeding gums?

- 1 yes
- 0 No

Do you have bad smell coming from your mouth?

- 1 yes
- 0 No

Personal health practices/use of dental services

How often do you brush your teeth?

- 1 never
- 2 several times a month (2-3 times)
- 3 once a week
- 4 several times a week (2-6 times)
- 5 once a day
- 6 2 or more times a day

What do you use for cleaning your teeth?

- 1 soap
- 2 salt
- 3 urine
- 4 local herbs

- 5 ash
- 6 toothpaste
- 7 nothing

Have you ever visited a dentist in your lifetime?

- 1 yes
- 0 No

Those who have visited the dentist

When was your last visit to the dentist?

- 1 Less than 6 months ago
- 2 6-12 months ago
- 3 More than 1 year but less than 2 years ago
- 4 2-5 years ago
- 5 More than 5 years ago

Where did you receive dental services?

- 1 private clinic
- 2 public health centre

What was the reason for your last dental visit?

- 1 routine check-up/ mandatory school check-up
- 2 emergency (tooth injury)
- 3 emergency (tooth ache)
- 4 having tooth(teeth)pulled
- 5 filling
- 6 root canal
- 7 others

Which means of transport did you use to access the preferred dental facility?

- 1 private car
- 2 walking
- 3 bus/taxi
- 4 bicycle
- 5 motorcycle

How much time did you spend at the dental facility from arrival to the time you left after treatment?

- 1 Less than 1 hour
- 2 1 to 2 hours
- 3 3 to 4 hours
- 4 Greater than 4 hours
- 5 I do not know

What was the average travel cost to and from the dental clinic?

- 1 Less than Ug. Sh. 4,000
- 2 Between Ug. Sh. 4100 10000
- 3 no money spent
- 4 More than 10000
- 5 I do not know

Do you feel the dental team listened well and gave you time to explain your problem?

- 1 yes
- 0 No

How would you describe the attitude of the oral health service providers that attended to you?

- 1 very good
- 2 good

- 3 average
- 4 below average
- 5 I do not know

HIV and dental treatment

Has the dentist ever asked for your HIV status before offering dental treatment?

- 1 yes
- 0 No

Have you ever hidden/withheld your HIV status from the dentist before receiving dental treatment?

- 1 yes
- 0 No

Have you ever felt not satisfied with the dental care you received because of your HIV status?

- 1 yes
- 0 No

Have you ever felt the dental care rendered to you was different from your friends and family whom you think do not have HIV?

- 1 yes
- 0 No

In general, how would you describe the way your dentist treated you?

- 1 excellent
- 2 good
- 3 fair
- 4 poor

10.0 Appendix B Questionnaire about factors influencing and barriers to access to dental care (Luganda)

Luganda

ID

Introductory questions for caregivers

Omwanawo / omuvubuka amanyi nti alina obulwadde?

- 1 Ye
- 0 Nedda
- 3 Omwana ye nayini ssimu

Akulabilira /omuzadde wo wali?

- 1 ye
- 0 nedda

Wali otutte ko omwana wo ew'omusawo w'ammanyo?

- 1 ye
- 0 nedda

Mwasinzira ku kki okusalawo awokufuna obujjanjabi bw'amannyo? Londako ekisinga

ku biino wamanga

akabanga okuva ewaka

sente z'obujjanjabi

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

ekifo twakiwuliramu emirembe

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu

- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

eneyissa y'abasawo gy'etuli

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

essawa z'okuggulawo n'okuggalawo eddwaliro zali zitwanguyira

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

kumpi newenfunira eddagala

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

waliwo eyatulagirirayo

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

Please record audio agreeing to assent or consent

Ensonga ezisobozessa ob'okukugira okufuna obujanjabi bw'amanyo

Elinnya ly'omunonyerezza

Ekikula

- 0 Mulenzi
- 1 Muwala

Emyaaka

Olimukibiina ki?

- 1 Pulayimale 1-3
- 2 Pulayimale 4-7
- 3 Siniya 1-4
- 4 Siniya 5 or 6
- 5 Ebyemikono/kosi
- 6 Sisoma

Abasawo gyonywera eddagalabatunulako mukamwa okulaba oba olina ekizibu?

- 0 Nedda
- 1 Olumu nolumu
- 2 Batera emirundi egyisinga
- 3 Buli lw'engenda muddwaliro

Wandiyagadde abasawo gyonywera eddagala okuwa kumagezi kubikwata ku mmannyo n'akamwa?

- 0 Nedda, ogwo simulimu gwabwe
- 1 Simayi oba ebyakamwa bibakwatako
- 2 Ye, kiba kinyamba kinenne

Ensonga ezikukugira oba okulemesa

Mulina ebintu bino ewaka wamwe ela bikola?

- 1 Telefina
- 2 Amasanyalaze
- 3 Akagali
- 4 Amazzi gemukozesa ewaka

- 5 Emmotoka
- 6 Toyi ey'amazzi
- 7 Essimu ey'omungalo
- 8 Komputa oba laptopu
- 9 Radiyo
- 10 bodaboda/pikipiki
- 11 furigi

Mumpangisa w'emubera?

- 1 ye
- 0 nedda

Enyumba yamwe ya bisenge bimeka?

- 1 kisenge kimu
- 2 bisenge bibiri
- 3 ebisenge bisuuka mu bibiri

Bantu bameka abasula munda munju

- 4 mbera nzeka
- 3 tubera babiri ewaka
- 2 tuli wakati wa 3-5 ewaka
- 1 tusuuka abantu 5 ewaka

Okutwaliza awamu embeera yawaka ely'etya?

- 1 nnungi nyo
- 2 nnungi
- 3 mbi
- 4 mbi nyo
- 5 simanyi

Ensonga ezikusobozessa okufuna obujjanjabi bw'amanyo

Otya okugenda ew'omusawo w' ammanyo?

- 1 sitya
- 2 Ntya mu katono
- 3 Ntila ddala

Ommanyi yo eddwalilo lyonna ely'ammanyo okumpi ne wemubela?

- 1 ye
- 0 nedda

Ommanyi yo eddwalilo lyonna ely'ammanyo elilinanye wotera okufunira.....?

- 1 ye
- 0 nedda

Ommanyi yo eddwalilo lyonna ely'ammanyo elilinanye oba elili okumpi ne wofunira eddagala?

- 1 ye
- 0 nedda

Wali olemesedwako obujjanjabi bw'ammanyo olwokuba olimulwadde?

- 1 Ye, emirundi mingi
- 2 Ye, emirundi mitono
- 3 Nedda silemesebwangako
- 4 Simanyi

Wali olemesedwako obujjanjabi bw'ammanyo olw'okutya okussasanya obulwadde?

- 1 Ye, emirundi mingi
- 2 Ye, emirundi mitono
- 3 Nedda silemesebwangako
- 4 Simanyi

Wali olemesedwako okufuna obujjanjabi bw'ammanyo olw'obutabawo ntegeka ku lunaku lwe lumu ne lwefunira ko eddagala?

- 1 Ye, emirundi mingi
- 2 Ye, emirundi mitono

- 3 Nedda silemesebwangako
- 4 Simanyi

Wali olemesedwako obujjanjabi bw'ammanyo olw'okulwala okuva kundwadde endala

- 1 Ye, emirundi mingi
- 2 Ye, emirundi mitono
- 3 Nedda silemesebwangako
- 4 Simanyi

Wali olemessedwako obujjanjabi bw'ammanyo olwa ssente?

- 1 Ye, emirundi mingi
- 2 Ye, emirundi mitono
- 3 Nedda silemesebwangako
- 4 Simanyi

Ani akusalilawo okulaba omusawo w'amannyo singa elinnyo liba likulumye?

- 1 abazadde bange
- 2 nze kenyini
- 3 andabilira
- 4 omusomesa wange
- 5 simanyi

Enabling resources for children above 14 years

Londako ekyokuddamu ku bibuzo wano manga

Bwemba ngenze ew'omusaawo w'ammanyo nga nina obuzibu n'ammanyo oba

mukamwa kange;

Ddamu nzikiliziganya nakyo oba sikiliziganya nakyo

kijja kuneetagisa ssente nyingi

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala

5 Simanyi

kijja kunemesa okugenda ku ssomero

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

sijja kuyisibwa bulungi

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

kijja kuntwalila obudde bungi

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

layini ey'okulinda omusawo ejjakuba mpanvu

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

Abazadde bange bajja kunzikiliza okugenda ew'omusawo w'ammanyo nga nina ebizibu n'ammanyo oba mukamwa kange

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

Omusomesa wange ajja kunzikiliza okugenda ew'omusawo w'ammanyo nga nina ebizubu n'ammanyo oba mukamwa kange

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

Okugenda ew'omusawo w'ammanyo nga netaaga obujanjabi bw'ammanyo kilungi eli obulamu

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

Okugenda ew'omusawo w'ammanyo nga netaaga obujanjabi bw'ammanyo kya mugaso

- 1 Nzikiliziganya ddala
- 2 Nzikiliziganya kitundu
- 3 Sikiliziganya mubulambalamba
- 4 Sikiliziganya nakyo ddala
- 5 Simanyi

Enabling resources part 3 for children below 14 years

Londako ekyokuddamu ku bibuzo bino wamanga

Bwemba ngenze ew'omusaawo w'ammanyo nga nina obuzibu n'ammanyo oba

mukamwa kange;

Ddamu ye oba nedda ku bibuzo bino wamanga

kijja kuneetagisa ssente nyingi

1 ye

- 0 nedda
- 3 simanyi

kijja kunemesa okugenda ku ssomero

- 1 ye
- 0 nedda
- 3 simanyi

sijja kuyisibwa bulungi

- 1 ye
- 0 nedda
- 3 simanyi

kijja kuntwalila obudde bungi

- 1 ye
- 0 nedda
- 3 simanyi

layini ey'okulinda omusawo ejjakuba mpanvu

- 1 ye
- 0 nedda
- 3 simanyi

Abazadde bange bajja kunzikiliza okugenda ew'omusawo w'ammanyo nga nina ebizibu n'ammanyo oba mukamwa kange

- 1 ye
- 0 nedda
- 3 simanyi

Omusomesa wange ajja kunzikiliza okugenda ew'omusawo w'ammanyo nga nina ebizubu n'ammanyo oba mukamwa kange

- 1 ye
- 0 nedda
- 3 simanyi

Okugenda ew'omusawo w'ammanyo nga netaaga obujanjabi bw'ammanyo kilungi eli obulamu

- 1 ye
- 0 nedda
- 3 simanyi

Okugenda ew'omusawo w'ammanyo nga netaaga obujanjabi bw'ammanyo kya mugaso

- 1 ye
- 0 nedda
- 3 simanyi

Need related factors

Bwogeerageranya embeera y'obulamu bwo ebadde etya okutwalira awamu?

- 5 nsuffu
- 4 nnungi nyo
- 3 nnungi
- 2 bwetyo bwetyo/ nnungi ko
- 1 mbi

Bwogeerageranya embeera y'amannyo n'akamwako ebadde etya okutwalira awamu?

- 1 Kayitirivu obulungi
- 2 Kalungi nyo
- 3 Kalungi
- 4 Bwekatyo bwekatyo
- 5 Kali bubi

Olimumativu n'embeeera y'akamwa n'ammanyo go?

- 1 Ndi mumativu nyo
- 2 Ndi mumativu
- 3 Silimumativu
- 4 Silimumativu nakatono

Olowooza wetaaga obujjanjabi bw'amannyo?

- 1 ye
- 0 nedda
- 3 simanyi

Olina obulumi nga buva mu manyo oba mukamwa ko?

- 1 ye
- 0 nedda

Olina ebibuno ebijja omusaayi?

- 1 ye
- 0 nedda

Olina olussu olubi oluva mukamwa?

- 1 ye
- 0 nedda

Personal health practices/use of dental services

Osenya emirundi emeka?

- 1 Sisenyezako ddala
- 2 Nsenya enfunda eziwela wakati w'ebbili n'omukaaga mu mwezi
- 3 Mulundi gumu mu wiki
- 4 Nsenya enfunda eziwela wakati w'ebbili n'omukaaga mu wiki
- 5 Mulundi gumu olunaku
- 6 Emirundi ebili oba ezisingako olunaku

Okozesa kki okulongosa amannyo go?

- 1 Sabuni
- 2 Omunnyo
- 3 Omusulo
- 4 Eddagala lyekinansi
- 5 Evvu
- 6 Eddagala ly'ammanyo ezungu

7 Tewali

Wali ogenze ko omusawo w'ammanyo?

- 1 ye
- 0 nedda

Those who have visited the dentist

Ddi lwewasemba okugenda ew'omusawo w'amannyo?

- 1 Teginawera myezi 6
- 2 Wakati w'emyezi 6 n'omwaka
- 3 Wakati w'omwaka nemyaka 2
- 4 Wakati w'emyaka 2-5
- 5 Nsusizza emyaka 5

Wa jjewafunila obujanjabi bw'amannyo omulundi ogwasembayo?

- 1 Eddwalilo ely'obwananyini
- 2 Eddwalilo elya gavumenti

Nsonga kki eyakutwala okulaba omusawo w'amannyo omulindi gwo ogwasembayo?

- 1 kugakeberako okwabulijjo oba okwetaagibwa essomero
- 2 nafuna akabenje
- 3 obulumi bwelinnyo
- 4 okukuulibwa elinnyo oba amannyo
- 5 okuzibikira ekituli mulinyo/kutekamu seminti
- 6 kunzijjanjaba busuwa bw'amannyo
- 7 ebirala

Wakozessa ntambula kki okutuuka ku ddwaliro ely'amannyo lyewagenda ko omulindi gwo ogwasembayo?

- 1 Emmotoka ey'obwananyini
- 2 Okutambula
- 3 Basi/takisi
- 4 Akagali
- 5 Pikipiki

Oteberezza bbanga kki lye wamala ku ddwalilo ely'amannyo okuva we watuuka ne wewavilawo nga bamazze okujanjaba?

- 1 Wansi w'esawa 1
- 2 Wakati w'esawa 1 ne 2
- 3 Wakati w'esawa 3 ne 4
- 4 Okusuka essawa 4
- 5 Simanyi

Oteberezza wakozesa/mwakozessa ssente meka mu ntambula ogenda nokuvaayo?

- 1 Tezasuka Ug. Sh. 4,000
- 2 Zali wakati Ug. Sh. 4100-10000
- 3 Tetwakozesa sente
- 4 Zasuka 10000
- 5 Simanyi

Abasawo bamannyo bakuwa obudde okuwuliriza ekikuluma?

- 1 ye
- 0 nedda

Wandinyonyodde otya empisa abasawo b'amannyo jjebakuyisaamu?

- 1 Yali nnungi nnyo
- 2 Yali nnungi
- 3 Yali bwetyo bwetyo
- 4 Teyali nnungi nga bwekyandisanidde
- 5 Simanyi

HIV and dental treatment

Omusawo w'amannyo yali akubuuzizza oba oli mulwadde nga tanaakujanjaba?

- 1 ye
- 0 nedda

Wali okisiza/okweka embera yo ey'obulwadde eli omusawo w'amannyo nga tanaakujanjaba?

1 ye

0 nedda

Wali owuliddeko obutali bumativu obw'obujanjabi bw'amannyo bwewafuna olw'obulwadde?

- 1 ye
- 0 nedda

Wali olowozezako/okuwulira nti obujanjabi bw'amannyo obwakuweebwa bwayawukana ku mikwano jjo oba famire yo bolowozza nti tebalina bulwadde?

- 1 ye
- 0 nedda

Okutwalira awamu, omusawo yakuyisa atya ng'ofuna obujjanjabi?

- 1 yampisa bulungi nyo ekisukulumye
- 2 yampisa bulungi nyo
- 3 yampisa bwatyo atyo
- 4 yampisa bubi nyo

11.0 Appendix C: Consent and assent forms (attachments)



Appendix 8a: Study Assent Form for Adolescents

INTRODUCTION

Kampala, Uganda

Co-investigator:

We are asking you to be in a research study. Research is not the same as treatment or dental care. The purpose of a research study is to answer scientific questions.

This assent form will give you information to help you decide whether joining the study is right for you. Please read this form carefully. We can read it with you if you want. If you do not understand, ask us questions. Also, you can talk to people whom you trust to help you decide about joining the study.

If you agree to join, you will sign on this form. We will offer you a copy of this form to keen.

PURPOSE OF THE STUDY

Tel: +256773288741, Whatsapp: +256773288741

E-mail address: mnakyonyi@gmail.com

We are asking you to join this study because you are an adolescent attending care in the selected HIV clinics in Kampala. You may or may not have had mouth diseases or tooth decay. The purpose of this study is to find out from children and adolescents seeking care in the selected HIV clinics in Kampala and determine the diseases of the mouth and teeth and

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learn more about the effects of these diseases on an individual's daily life. Some of the questions we are asking are:

- Currently, what is the number/percentage of children and adolescents with mouth diseases and tooth decay?
- What treatment do the children and adolescents need?
- How do these mouth diseases and dental decay affect the lives on children and adolescents?
- Which factors help and prevent you from getting dental care among the HIV infected adolescents?

NUMBER OF PARTICIPANTS

Up to 1131 children and adolescents will be in this study. 90 children and adolescents will be recruited in the pilot study and 1041 children and adolescents in the actual study from selected HIV clinics in Kampala (Mulago Immune Suppressive Syndrome (ISS) clinic, Kawaala Health Centre IV, Kisenyi HCIV, Kiswa HCIII and Nsambya Homecare)

STUDY DURATION & STUDY VISIT

If you want to join the study, we can enroll you in it today.

For the 940 study participants, the enrollment visit is the only study visit while there will be two study visits for the 90 participants included in the pilot study, and another 104 to have one of the study procedures (interview about one's viewpoint on the effect of the oral problems on daily life) redone. You could fall into any of these categories. There are no other study visits.

STUDY PROCEDURES

The following are details of the study procedures

Oral interview: Before the clinical examination, a questionnaire will be administered to each study participant in form of an oral interview to obtain information on several aspects. The questions involve the following topics; age and sex, perception of one's oral status and its effect on their daily life, oral health seeking behaviour, oral health habits, family information on parents' education, occupation, number of children in the family, family head, decay among other family members, and housing conditions. The proposed questionnaire will be administered inside a room with both the research assistant and study participant sitting in the room or by a telephone interview.

Oral examination: A dental check-up will be carried by a trained dentisity is determine the PFROVED participants' oral health status. The dental checkup will be done with the participant lying on 2020 a portable dental chair under a shade. A disposable mouth mirror and dettal probe will be carried by a trained dental probe will be used to clean the teeth of soft food debris.

POSSIBLE RISKS OF STUDY PARTICIPATION

We will do our best to protect your personal information. No substantial risk is foreseen in this study. However, you will spend some of your precious time while participating in this study

POSSIBLE BENEFITS OF STUDY PARTICIPATION

You will benefit from this study by getting a report about your oral health. In addition, if found with dental problems, you will be informed and referred to the appropriate dental clinics for treatment. If found with a problem considered a dental/medical emergency, efforts will be made by the study team to provide appropriate care or refer you to an appropriate doctor. However, the information we will obtain in this study may help others in the future with dental caries. The data obtained from this study will help the team of dental practitioners to know the results obtained will help a team of medical workers to know the level of oral MAKERENE UNIVERSITY



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P.O. BOX 7072, KAMPALA

disease among children and adolescents at the selected HIV-care clinics in Kampala and the effects on their daily lives, so that the necessary planning can be done to address some of these health problems. The results will also be used to put in place appropriate measures of oral health education and oral disease prevention.

PRIVACY, CONFIDENTIALITY AND USE OF INFORMATION

We will label your information with a code number, not your name or other information that could be used to identify you. Thus, your identity will not be revealed in any presentation or publications of this study.

Confidential information will be used for research purposes only. The information obtained in the course of the study will not be communicated to anyone else without your written permission.

The study team will be the only one with the authority to access the collected data. The information obtained from all these procedures in this study will be entered in a secure computer and will be used to answer study questions. We will label your information with a code number, not your name or other information that could be used to identify you.

However, the School of Health Sciences Research and Ethics Committee and the Uganda National Council for Science and Technology (UNSCT) may have access to private information that identifies the research participants by name where applicable.

COMPENSATION

After completing the clinical examination and filling the questionnaire, each study participant you will be given 10000/= as compensation for your time.

ALTERNATIVES TO TAKING PART IN THIS RESEARCH STUDY

You do not have to join this study. If you have a problem with your teeth or mouth, you can choose to consult any other dentist to gain information about your condition.

VOLUNTARY PARTICIPATION

Entry into the study is entirely voluntary and no penalty will be incurred for nonparticipation. Should you choose to withdraw from the study anytime and for any reason, you are free to do so and this will not affect anything related to your well-being. Please tell us if you decide to leave the study. In case you are not happy with your treatment, you may contact any of my mentors:

- 1. Professor Philippa Musoke, Makerere University Phone contact 077242926901. UP REALTH SCIENCES
- 2. Dr Sabrina Bakeera-Kitaka, Makerere University Phone contact 0772401750NDMENT APPROVED

COST TO YOU



There is no cost to you for being in this study. You do not have to pay for the study visit. All other dental costs, outside of this study will be paid by you or your fite the the study will be paid by you or your fite the the study will be paid by you or your fite the the study will be paid by you or your fite the the study will be paid by you or your fite the the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fit the study will be paid by you or your fite the study will be paid by you or your fite the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or your fit the study will be paid by you or you by you or you or you by you or you by you or you or you or you by you or

RESEARCH-RELATED INJURY

The procedures in this study are normal clinical procedures, so we don't expect injuries from it. If you get sick or injured during the study, contact us immediately. We will tell you about the care that we can give here. For the care that we cannot provide, we will explain how we will help you get care elsewhere and efforts will be made for it to be at no cost to you.

PROBLEMS OR QUESTIONS

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If you have any other questions, please ask the study staff. In the future, if you have any questions about this study or if you want to leave this study, please contact: Dr. Catherine Mwesigwa

+256 772611035, Whatsapp: +256 772611035, +256773288741 E-mail address: drcathymwesigwa@gmail.com

If you have questions related to your rights and welfare, you can contact the Chairperson of Makerere University School of Health Sciences Research and Ethics Committee - Dr. Paul Kutyabami on telephone number (256-772404970) / 256)-0200-903786) or Uganda National Council for Science and Technology on telephone number (0414705500)

SPONSORS OF RESEARCH PROJECT AND ORGANISTION AFFLIATION OF THE RESEARCHERS

This study is sponsored by NURTURE Mentorship Programme, School of Medicine, College of Health Sciences, Makerere University and NORPART joint research-based education in dentistry in Norway and East Africa 2019/2023

The principal investigator, Dr. Catherine Mwesigwa is a lecturer name School, OF HEALTH SCIENCES Dentistry, School of Health Sciences, College of Health Sciences, Makerere University. The co-investigator, Dr. Maria Gorretti Natyonyi is a lecture in the second s The co-investigator, Dr. Maria Gorretti Nakyonyi is a lecturer in the Department FEB 2020 Dentistry, School of Health Sciences, College of Health Sciences, Makerere University.



FEED BACK AND FUTURE CONTACT

A series of seminars will be organized at the selected HIV clinics to provide teedback on the research findings and data that has clinical relevance to the research participants will be made available to the research participant. We can give you the study results on the day of the seminar if you want them.

APPROVAL BY AN ACCERDITED UGANDA BASED RESEARCH ETHICS COMMITTEE

This study was approved by the Research Ethics Committee of the School of Health Sciences, College of Health Sciences, Makerere University Uganda.

PARTICIPANT'S STATEMENT & SIGNATURE

Study staff has explained the study to me. I agree to join the study. I have had a chance to ask questions. Study staff has told me that if I have future questions about the research, I can ask one of the contacts listed above. By signing this form I do not give up any rights that I have as a research participant.

If you have read this assent form or had it explained to you and you understand it, please sign your name.



Appendix 8b: Study Assent Form for Adolescents (Luganda Version)



MAKERERE



ORAL HEALTH QUALITY OF LIFE AND DENTAL TREATMENT NEEDS 7072, KAMPALA HIV CLINICS: A CROSS-SECTIONAL STUDY

Akulidde okunoonyereza

Dr. Catherine Lutalo Mwesigwa Department of Dentistry College of Health Sciences, Makerere University P.O. Box 7072, Kampala-Uganda Kampala, Uganda Essimu: +256 772611035, Watisappu: +256 772611035

Yiimeyiro: dreathymwesigwa@gmail.com

Ayamba okunoonyereza Dr. Maria Gorretti Nakyonyi Department of Dentistry College of Health Sciences, Makerere University P.O Box 7072, Kampala- Uganda Essimu: +256773288741, Whatisappu: + 256773288741 Yiimeyiro: mnakyonyi@gmail.com



OKWEYANJULA: Nze (akiikiridde) Dr Catherine Mwesigwa wamu ne Dr. Maria Gorretti Nakyonyi okuva mu Department of Dentistry, Makerere University.

Osabibwa okweetaba mu kunoonyereza kuno. Okunoonyereza si kye kimu n'okujjanjaba ebituli mu mannyo. Ekiwandiiko kino kijjakuyamba okusalawo oba kikugwanidde okwetaba mukunoonyereza kunno. Gyisome ogyetegereza bulungi. Bwoba oyagagadde, tusobola okugikusomera.

Osobola okwogera n'abantu beweekakasa okukuyamba okusalawo oba ng'omwanawo yalyetaabe mu kussoma kuno.

Ssinga okkiriza okwetaba mu kussoma kuno, ojja kussa omukono gwo ku kiwandiiko kino. Tujja kukuwa kkope y'ekiwandiiko kino ogyeeterekere.

OMUGASO GW'OKUNONYEREZA

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Totekkako mukono kukiwandiko kino bwe kiba nga terina stampu ya IRB ekirizibwa, oba olunaku bweluba lwayitako

Osabibwa okweetaba mu kunoonyereza kuno kubanga olimuvubuka/mwana affuna obujjanjabi mumalwaliro agonokoddwa mu Kampala. Kisoboka okuba nti olina obulwadde bwamannyo oba nakamwa. Ekigendeerera ky'okunoonyereza kuno kwe kwagala okumanya obulwadde bwakamwa n'amanyo mu baana nabavubuka abafuna obujjanjabi okuva mumalwaliro agolendedwa nga gali mu Kampala disitulikiti era n'okutegeera engeri obuzibu bunno bwebutawanya obulamu bwabwe obwabulijjo. Ebimu kubibuuzo ebinabuuzibwa byebino wamanga;

- Abaana bameka abalina obulwadde bwakamwa n'amannyo?
- Abaana bano betaaga bujjanjabi bwangeri ki?
- Obulwadde bunno butawanya butya obulamu bwabwe obwabulijjo?
- Bintu kki ebiziyizza oba ebisobozessa okufuna obujjanjabi bw'amanyo mu bavuka abaali ku ddagala?

OMUWENDO GW'ABEETABI

Abaana n'abavubuka nga 1131 bebajja okubeera mu kusoma kuno. Abaana n'abavubuka 90 bebajja okuyingizibwa mu kusoma okw'okugezesa ate 1041 bebajja okubeera mu kusoma kwennyini.

EBANGA LY'OKUNNONYEREZA

Bwoba oyagadde okwetaba mukussoma kunno, osobola okuyingizibwa olwaleero oba lwona

Abaana/abavubuka 940 bebajja okwetaba mukusoma omulundu gunukgwoka ate 104 salkida ES omulundi ogwokubiri okuddamu ebibvuuzo ebikwatagana kumberra odbulanu nakaniwa oba ED amanyo gabwe. Abaana nabavubuka kikumi bebajja okusasati su DWEN nakaniwa oba amanyo gabwe. Abaana nabavubuka kikumi bebajja okugezesebwa Rg okusoma kwenyini 2.8 FEB 2020 tekunatandika. Oyinza okugwa kukimu kukiti ky'abantu band.

ENTAMBULA Y'OKUNNONYEREZA

Okubuuzibwa ebibuuzo: Ngatonakeberebwa mannyo, onaburzibwa ebibuuzo ekiawa?aLA kubintu ebyenjawulo mubulamu bwo. Ebimu kubibuuzo byebinp @amanga:- emyaka gyo, obuotne bwekisajja ob'ekikazzi, endowooza kumbeera vobulome buotosia. y'obujjanjabi bwakamwa n'anannyo, endabirira yakamwako, ebikwata ku bazadde oba abakulabirira ng'obuyigiriza n'emirimu gyebakola, akulira amaka mwobera, abaana bozalibwa nabo, n'embeera yawaka wobera. Ebibuuzo bijja kubuzibwa mukasenge ng'otudde n'omuntu ayamba mukubiririza kunno.

Okeberebwa akamwa: Omusawo w'amannyo omutendeke ajjakeberebwa akamwa n'amannyo okulaba embeera yabyo. Ojjakwebaka kuntebe eyegolola era obuuma obunakozesebwa bujja kuba bupya nga bubo weka era oluvanyuma busulibwe. Ngatonakeberebwa, amannyo gajjakulongosebwa ne kapamba okujjako emmere yonna eba ekwatiddeko.

OBUZIBU /OKUNYIGIRIZIBWA: Tujja kukola kyonna ekisoboka okukuuma ebikwaatak nga bya kyama. Era ebinakolebwa mu kussoma kunno kikakassibwa nti ssi byabulabe eri ggwe. Naye obuddebwo bwowadeyo okwetaba mukussoma kunno bwa muwendo.

OKUGANYURWA: Ogya kuganyulwa mu kussoma kuno mu butereevu ngoweebwa alipoota ekwatagana kumbeera yobulamu bwakamwa n'amannyo go. Wabula ssinga osangibwa n'ekizibu ky'amannyo, tujja kutegeeza era tukulagirire eddwaaliro ly'amannyo eddungi woyinza okufuna obujjanjabi. Bwoba osingiddwa n'ekizibu ekyetaagise obujjanjabi obwamangu ddala, ttiimu yabasawo ejjakuba evvunanyizibwa obujjanjabi buno oba okuwereza eri omukuggu asobola okutusaako obujjanjabi obw'etagisa. Ebibuuzo ebibuuzibwa, n'okukebera okukolebwa wamu n'ebizuulibwa bijja kuyamba ekibinja ky'abasawo okumanya obungi bw'obulwadde bw'akamwa n'amannyo, nebizibu ebibuvaamu. Era kijjakuvamba entegeka ekolebwa okujjanjaba abalwadde mukitongole ERSITY

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Totekkako mukono kukiwandiko kino bwe kiba nga terina stampu ya IRB ekirizibwa, oba olunaku bweluba lwayitako



kukozesebwa okubangawo ennuŋŋamu Ebizuuliddwa bijja engeri gyebujja. ey'okuyigirizaamu enkuuma y'amannyo wamu n'okwewala ebituli mu mannyo.

OKUKUUMA EKYAAMA N'E NKWATA YEBIKUFAAKO: Ebikwaata ku mweetabi bijia kuwandiikibwaako n'ennamba ya kkoodi, wabula ssi mannyago oba ekintu ekirala kyonna ekisobola okwatukiriza. N'olwekyo ekikulaga ngagwe omuntu tekijja kulagibwa mu kiwandiiko kyonna ekiva mu kussoma kuno. Ebiwandiiko byonna ebikozesebwa mu kusoma kuno bijja kusibibwa mu kkabada eriko n'ekisumuluzo. Ebiggyibwa mu kukebera kuno kwonna okw'okusoma bijja kuyingizibwa mu kkomputa era bikozesebwe okuddamu ebibuuzo eby'okusoma kuno.

Ebikwaatako eby'ekyaama bijja kukozesebwa mu kunoonyereza kwokka. Ebikwaatako eby'ekyaama ebikunnanyizibwa mu bbanga ly'okusoma kuno tebijja kubuulirwa muntu yenna nga tetumaze kufuna lukusa kuva gy'oli.

OKWEETABA OKW'EKYEYAGALIRE: Okuyingira mu kusoma kuno kwa kyeyagalire era tewali kijja kukutuukako olw'obutabeera mu kusoma kuno. Ssinga osalawo okuva mu kusoma kuno essaawa yonna olw'ensonga yonna, oliwaddembe okukikola era kino tekijja kukukosa mungeri yonna.

BY'OYINZA OKUKOLA SSINGA TEWEETABYE MU KUNOONYEREZA OKW'OKUSOMA: Tekikwetagisa kweetaba mu kusoma kuno. Ssinga wabaawo obuzibu n'amannyogo oba akamwa, osobola okweebuuza ku musawo w'amannyo omulala yenna okusobola okufuna ebisingawo ku mbeerayo. Bwoba tosanuse nenkwata oba enzijjanjaba gyofunye, oyinza okwatagana nabasingako ng'obakubira kussimu:

- 1. Professor Philippa Musoke, Makerere University Essimu 0772429289
- 2. Dr Sabrina Bakeera-Kitaka, Makerere University Essimu 0772401790

Okusasula: Tewali mutemwa guteereddwawo eri ggwe olw'okubeera mu kusoma kuno. Teweetaga kusasula olw'okujja okutulaba oba olw'okukeberebwa kwonna. Wabula, ssinga ofuna obujjanjabi bwonna obuli wabweeru bw'okusoma kuno, ojja kwesasulirira oba akuvunayizibwa okusasasulira yinsuwaye (ssinga alina yinsuwa) okugeza ssinga abeera aweerezeddwa mu kifo ekirala okujjanjabibwa. Ekinaaba ekyenjawulo bwebujjanjabi abasawo ku ttiimu bwebawa obwetagisa amangu ddala, obwo tebujja kussasulibwa.

OBUVUNE OBWEKUUSA KU KUNOONYEREZA: Ekibikolebwa mu kusoma kuno bye byabulijjo ebikolebwa mu bujjanjabi, n'olwekyo tetusuubira kubeerawo buvune bwonna okubuvaamu. Ssinga olwaala oba ofuna obuvune bwonna ng'oli mu kusoma kuno, osabibwa otutuukirire mu bwangu. Tujja kubuulira obujjanjabiki bw'olina okufuna. Olw'obujjanjabi bwe tutasobola kuwa, tujja kuweereza mu kifo ekirala.

Obuvune obumu sibulwadde bwamubiri naye buyinza okuba kumbeera y'obuntu MAKERERE DRIVERSITY

OBUZIBU OBA EBIBUUZO:

CHOOL OF REALTH SCIENCES Ssinga olina ebibuuzo ebirala byonna ebyekuusa ku kusoma kuno, osabibwa etuukinirei T APPROVED Dr. Catherine Lutalo Mwesigwa 2.8 FEB 2020 Essimu +256 772611035, Watisappu: +256 772611035

Yimeyiro: drcathymwesigwa@gmail.com

Wamu ne Dr. Maria Gorretti Nakyonyi

Essimu +256 773288741, Watisappu: +256773288741

Yimeyiro: mnakyonyi@gmail.com

Ssinga olina ebibuuzo byonna ebyekuusa ku kusoma kuno naye nga walyagadde okwogera n'omuntu omulala yenna atali mu kusoma kuno, osobola okutuukirira:

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Totekkako mukono kukiwandiko kino bwe kiba nga terina stampu ya IRB ekirizibwa, oba olunaku bweluba lwayitako



INSTITUTIONAL REVIEW BOARD

P.O. BOX 7072, KAMPALA

×

• Ssentebe – Dr. Paul Kutyabami

School of Health Sciences Research and Ethics Committee (MakSHSREC) Makerere University + 256-772404970 / +256)-0200-903786)

• Uganda National Council of Science and Technology Essimu: (+256 414705500)

Plot 6, Kimera Road, Ntinda P.O. Box 6884 Kampala, Uganda

OKULIYIRIRWA: Oluvannyuma lw'okumaliriza okukeberebwa okw'obujjanjabi wamu n'okuddamu ebibuuzo, onoweebwa ebintu ebirowoozebwa ebigwanidde emyaka ggyo era nakasenya okukubiriza okulabirira akamwaako obulungi bulijjo. Kino kiba kukwebaza olwobudde bwotuwadde.

ABAWADDEYO ENSIMBI Z'OKUSOMA KUNO WAMU N'EKITONGOLE

ABANOONYEREZI MWE BASIBUKA:Okusoma kuno kusasuliddwa ppulogulaamu ya NURTURE Mentorship Programme School of Medicine, College of Health Sciences, Makerere University ne NORPART Programme ekitongole ekyatebwawo wakati wa East Africa ne Norway mu byokunonyereza. Akulidde okunoonyereza kuno, Dr.Catherine Mwesigwa musomesa mu Department of Dentistry, School of Health Sciences, College of Health Sciences, Makerere University wamu ne Dr. Maria Gorretti Nakyonyi omusomesa mu Department of Dentistry, School of Health Sciences, Makerere University.

BY'OTUBUULIRA OBA OKUTUUKIRIRWAMU EDDA: Ssemina zijja kutegekebwa ku ddwaliro okusobola okubawa ebivudde mu kunoonyereza kuno wamu n'ebyo ebibakwaatako eby'obujjanjabi ebinaabeera bizuuliddwa. Tusobola okuwa ebivudde mu kunoonyereza kuno ku lunaku lwa ssemina ssinga obyagadde.

OKUKAKASIBWA AKAKIIKO AKAKWAASISA EMPISISA MU KUNOONYEREZA AKAMANYIDDWA MU UGANDA: Okunoonyereza kuno kwakakasibwa akakiiko akakwaasisa empisa mu kunoonyereza aka School of Health Sciences, College of Health Sciences, Makerere University Uganda.

KY'OSAZEEWO: Ntegeezeddwa ebikwaata ku kusoma kuno. Nsazeewo okwetabamu. Nzikiriziddwa okubuuza wembadde sitegedde era ntegezeddwa wensobola okwebuzaako singa mba nina ebibuuzo gyebujja. Nkitegedde nti bwenteeka omukono ku kiwandiiko kino byonna ebingwaniddee ng'eyatabye mu kusoma bijagoberebwa. Nsomye oba nsomeddwa ekiwandiiko kino nekinyonyolwa era nenkitegeera. Era nzisaako omukonwo gwange wamanga

Erinnya ly'omwana	omukonogwe	Ennaku z'omwezi
Emyaka gy'omwana		
Enzikiriziganya mu kwogera		MAKERERE UNIVERSITY SCHOOL OF HEALTH SCIENCES APPROVED VALID UNTIL * 27 FEB 2021 *
Erinnya ly'omwana		RESEARCH & ETHICS COMMITTEE P. O. BOX 7072, KAMPALA
Totekkako mukono kukiwand kino bwe kiba nga terina star ya IRB ekirizibwa, oba oluna bweluba lwayitako	IKO npu ku 92 MAKE SCHOOL AMEND * INSTITUT P.O. B	REREDIARUZIONWEZI UF HEALTH SCIENCES MENT APPROVED 2 8 FEB 2020 ★ TIONAL REVIEW BOARD OX 7072, KAMPALA

Appendix 7a: Study Consent Form for Parents (English Version)



MAKERERE

COLLEGE OF HEALTH SCIENCES SCHOOL OF HEALTH SCIENCES DEPARTMENT OF DENTISTRY

Study title:

ORAL HEALTH QUALITY OF LIFE AND DENTAL TREATMENT NEEDS AMONG HIV+ PAEDIATRIC ATTENDING THE SELECTED HIV CLINICS: A CROSS-NOTE: Do not sign this consent form SECTIONAL STUDY

Principal investigator

it it does not have an IRB approval stamp, or if the date has lapsed Dr. Catherine Lutalo Mwesigwa Department of Dentistry College of Health Sciences, Makerere University P.O. Box 7072, Kampala-Uganda Kampala, Uganda MAKERERE UNIVERSITY +256 759998964/ +256 772611035, Whatsapp: +256 772611035 SCHOOL OF HEALTH SCIENCES APPROVED E-mail address: drcathymwesigwa@gmail.com VALID UNTIL **Co-investigator** Dr. Maria Gorretti Nakyonyi 2 7 FEB 2021 Department of Dentistry College of Health Sciences, Makerere University **RESEARCH & ETHICS COMMITTEE** P.O Box 7072, Kampala-Uganda P. O. BOX 7072, KAMPALA Kampala, Uganda +256 773288741, Whatsapp: +256773288741

E-mail address: mnakyonyi@gmail.com

Introduction

We are (representing) Dr. Catherine Lutalo Mwesigwa and Dr. Maria Gorretti Nakvonvi from the Department of Dentistry, School of Health Sciences, College of Health Sciences Makerere University.

Your child/adolescent is being requested to take part in this study/research. Research is not the same as treatment or dental care. The purpose of a research study is to answer scientific questions. The major focus of this study is to determine Oral Health Quality of Life and Dental

Treatment Needs among HIV+ Paediatric Patients attending the selected HIV clinics

This consent form will give you information to help you decide whether it is right for your child/adolescent to join the study. Please read this form carefully. If you do not understand anything, ask us questions by calling the principal investigator, the contact is provided above. Your airtime for that call will be reimbursed. You can talk to people whom you trust to help you decide whether your child/adolescent should join the study.

If you agree that your child/adolescent should join, you will sign on this form. We will offer you a copy of this form to keep.

Brief background and rationale of the study:

Despite the need for holistic management of HIV patients, there seems to be a gap with regard to dental care. Unfortunately, the aspects concerning access to oral health care and unmet dental treatment needs in this population have not yet been researched. This study intends apycover the

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following scope of aspects like oral health related quality of life, dental treatment needs and factors that help or prevent access to dental care services among this category of patients.

Purpose of the Study: The purpose of this study is to find out the level of dental disease among children and adolescents seeking care in the selected HIV clinics in Kampala and how easily they find dental services. determine the diseases of the mouth and teeth and learn more about the effects of these diseases on an individual's daily life. Some of the questions we are asking are:

- Currently, what is the number/percentage of children and adolescents with mouth diseases and tooth decay?
- What treatment do the children and adolescents need?
- How do these mouth diseases and dental decay affect the lives on children and adolescents?
- Which are the factors that help or prevent getting dental care among the HIV infected children and adolescents?

Study procedure: Your child/adolescent has been identified to participate in this study and we require your consent. Where a child is considered very young to answer the questions asked, we will request you to answer these questions regarding your child's health. For at obser child or provide the LES he/she will be asked questions about himself/ herself, perception of their oral, status, and health seeking behaviour, oral health habits, family information on parents' Addication, occupation, number in the family, family head, dental decay among other family members, and housing to be done on her/him.

The estimated duration the research participant will take to in the research project 72, KAMPALA Each research participant will spend an average of about 20 minutes in On Tinterview answering questions on the questionnaire. The estimated time will be equivalent to telephone interviews as well. Number of participants: Up to 1131 children and adolescents will be in this study, 90 of whom will be recruited in the pilot study and 1041 adolescents in the actual study.

Benefits: Your child/ adolescent will benefit from this study by getting a report about his/her oral health. In addition, if found with dental problems you will be informed and referred to the appropriate dental clinics for treatment. If found with a problem considered a dental/medical emergency, efforts will be made by the study team to provide appropriate are or refer to anappropriate doctor. However, the questions asked, examination, and results obtained will help a team of medical workers to know the level of oral disease among children and adolescents under HIV care at the selected HIV clinics and the effects on their daily lives, so that the necessary planning can be done to address these health problems. The results will also be used to put in place appropriate measures of oral health education and oral disease prevention.

Risks /Discomforts: We will do our best to protect your child's/ adolescent's personal information. No substantial risk is foreseen in this study. However, you and your child/adolescent will spend some of your precious time while participating in this study

Alternatives to Taking Part in this Research Study: Your child/adolescent does not have to join this study. If he/she has a problem with their teeth/mouth, he/she can choose to consult any other dentist to gain information about their condition.

Cost: There are no costs to you or your child/ adolescent for being in this study. You or your child/adolescent does not have to pay for the study visit or for any examination.

However, all other dental costs outside of this study will be paid by you or your health insurance carrier (if you have insurance) for example in case of referral for treatment.

Compensation: After completing the clinical examination and filling the questionnaire, you or your adolescent will be compensated for their time with either cash or items that amount to Ugandan shillings 15000. In addition, they will be given a toothbrush to encourage good oral hygiene practices. **Reimbursement:**

The cost of compensation will be based on travel distance to the site which includes transport expenses and time spent at the study site.

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Research-related injury: The procedures in this study are normal clinical procedures, so we don't expect injuries from it. If your child/adolescent gets sick or injured during the study, you should contact us immediately. We will tell you about the care that we can give them. For the care that we cannot provide, we will refer him/her to other places.

Privacy and confidentiality: We will label each participant's information with a code number, not their name or other information that could be used to identify them. Thus, the identity of your child/adolescent will not be revealed in any presentation or publications of this study. Paper records will be kept under lock and key. The information obtained from all these procedures in this study will be entered in a secure computer and will be used to answer study questions.

Confidential information will be used for research purposes only. Confidential information obtained in the course of the study will not be communicated to anyone else without written permission from you. The local Research Ethics Committee (REC) and Uganda National Council for Science and Technology (UNCST) as entities which may have access to private information that identifies the research participants by name.

Voluntary participation: Entry into the study is entirely voluntary and no penalty will be incurred for non-participation. Should you or your child/ adolescent choose to withdraw from the study anytime and for any reason, all are free to do so, and this will have no consequences.

Problems or questions about the study:

If you have any other questions about this study, please contact: Dr. Catherine Lutalo Mwesigwa

+256 772611035, Whatsapp: +256 772611035 E-mail address: drcathymwesigwa@gmail.com

Dr. Maria Gorretti Nakyonyi

+256 773288741, Whatsapp: +256 773288741



If you have any questions about the study but want to talk to someone else who is not a part of the study, you can contact;

Chairperson Dr. Paul Kutyabami

School of Health Sciences Research and Ethics Committee (MakSHSREC)

Makerere University +256-772404970 or +256 0200903786

Uganda National Council of Science and Technology,

Tel: (+256 414705500) Plot 6, Kimera Road, Ntinda P.O. Box 6884 Kampala, Uganda

Sponsors of research project and organization affiliation of the researchers: This study is sponsored by NURTURE Mentorship Programme School of Medicine, College of Health Sciences, Makerere University and NORPART, establishment of joint research-based education in dentistry in Norway and East Africa. The principal investigator and co-investigator, Dr. Catherine Mwesigwa and Dr. Maria Gorretti Nakyonyi respectively are lecturers in the Department of Dentistry, School of Health Sciences, College of Health Sciences, Makerere University.

Dissemination of results: The research participants will get feedback on findings and progress of the study and their oral health assessment and that any new information that affects the study or data that has clinical relevance to research participants (including incidental findings) will be made available to research participants and/or their health care providers.

Feedback and future contact: A series of meetings will be organised at the selected HIV clinics to provide feedback on the research findings and data that has clinical relevance to the research participants will be made available to the research participant. We can give you the study results on the day of the seminar if you want them.

Approval by an accredited Uganda based research ethics committee: This study was approved by the Research Ethics Committee of the School of Health Sciences, College of Health Sciences, Makerere University Uganda.

NOTE: Do not sign this consent form if it does not have an IRB approval stamp, or if the date has lapsed 104



Consent statement: I have been informed of the study to determine the oral health status and its effect on the daily life of children and adolescents undergoing HIV care in the selected HIV clinics in Kampala.

The purpose and nature of the study, the benefits and risks have all been explained to me. I was also informed that the information given will be kept confidential and that my child's participation in this study is entirely voluntary and no consequences will result if I refuse him/ her to participate or withdraw from the study.

I hereby give my informed consent for my adolescent to participate in this study.

Name of Parent	Parent's signature or	Thumbprint	Date		
OR					
Verbal consent for adolescents Name of Parent	aged 14-17 years		Date		
Name of Child/Adolescent	Participant's signature or	Thumbprint	Date		
Name of Witness	Signature		Date		
Study staff Name	Signature		Date		
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NOTE: Do not sign this consent val					



Appendix 7b: Study Consent Form for Parents (Luganda Version)



MAKERERE

UNIVERSITY

COLLEGE OF HEALTH SCIENCES SCHOOL OF HEALTH SCIENCES DEPARTMENT OF DENTISTRY

Omulamwa:

ORAL HEALTH QUALITY OF LIFE AND DENTAL TREATMENT NEEDS AMONG HIV+ PAEDIATRIC PATIENTS ATTENDING THE SELECTED HIV CLINICS: ON A MAKERERE ON A VERSITY CROSS-SECTIONAL STUDY

Akulidde okunoonyereza

Dr. Catherine Lutalo Mwesigwa Department of Dentistry College of Health Sciences, Makerere University P.O. Box 7072, Kampala-Uganda Kampala, Uganda Essimu: +256 772611035, Watisappu: +256 772611035

Yiimeyiro: drcathymwesigwa@gmail.com

Ayamba okunoonyereza

Dr. Maria Gorretti Nakyonyi Department of Dentistry College of Health Sciences, Makerere University P.O Box 7072, Kampala-Uganda Kampala, Uganda Essimu: +256 773288741, Watisappu: +256773288741 Yiimeyiro: mnakyonyi@gmail.com



RESEARCH & ETHICS COMMITTEE

P. O. BOX 7072, KAMPALA

OKWEYANJULA: Nze (akiikiridde) Dr Catherine Mwesigwa wamu ne Dr. Maria Gorretti Nakyonyi okuva mu Department of Dentistry, Makerere University.

Omwanawo /omuvubuka asabibwa okweetaba mu kunoonyereza kuno. Okunoonyereza si kye kimu n'okujjanjaba ebituli mu mannyo. Ekigendeerera ky'okunoonyereza kuno kwe kwagala okuddamu ebibuuzo bya ssaayansi. Mu kino twaagala okumanya obulwadde bwakamwa n'amanyo mu baana nabavubuka abafuna obujjanjabi okuva mumalwaliro agalondedwa nga gali mu Kampala disitulikiti era n'okutegeera engeri obuzibu bunno bwebutawanya obulamu bwabwe obwabulijjo, ebintu ebiziyizza oba ebisobozessa abavubuka abali ku ddagala okufuna obujjanjabi bw'ammanyo.

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Totekkako mukono kukiwandiko kino bwe kiba nga terina stampu ya IRB ekirizibwa, oba olunaku bweluba lwayitako **Okusasula:** Tewali mutemwa guteereddwawo eri ggwe oba omwanawo olw'okubeera mu kusoma kuno. Omwanawo omuvubuka teyeetaga kusasula olw'okujja okutulaba oba olw'okukeberebwa kwonna.

Wabula, ssinga afuna obujjanjabi bwonna obuli wabweeru bw'okusoma kuno, ojja kumusasulirira oba ye okweesasulira oba okusasasulira yinsuwaye (ssinga alina yinsuwa) okugeza ssinga abeera aweerezeddwa mu kifo ekirala okujjanjabibwa. Ekinaaba ekyenjawulo bwebujjanjabi abasawo ku ttiimu bwebawa obwetagisa amangu ddala, obwo tebujja kussasulibwa.

Okuliyirirwa: Oluvannyuma lw'okumaliriza okukeberebwa okw'obujjanjabi wamu n'okuddamu ebibuuzo, gwe n'omwanawo omuvubuka mujja kuweebwa akasiimo olwobudde bwe/bwamwe nga ka sente n'ebintu ebyenkana omuwendo gwe sente ogwa silingi za Uganda omutwalo gummu n'ekitundu Okwongereza kw'ekyo, omwana oba omuvubuka ajja kuweebwa akasenya okumukubiriza okulabirira akamwaake obulungi bulijjo.

Obuvune obwekuusa ku kunoonyereza: Ekibikolebwa mu kusoma kuno bye byabulijjo ebikolebwa mu bujjanjabi, n'olwekyo tetusuubira kubeerawo buvune bwonna okubuvaamu. Ssinga omwanawo omuvubuka alwaala oba afuna obuvune bwonna ng'ali mu kusoma kuno, osabibwa otutuukirire mu bwangu. Tujja kumubuulira bujjanjabiki bw'alina okufuna. Olw'obujjanjabi bwe tutasobola kumuwa, tujja kumuweereza mu bifo ebirala.

Okukuuma ekyaama: Ebikwaata ku mweetabi bijja kuwandiikibwaako n'ennamba ya kkoodi, wabula ssi mannyage oba ekintu ekirala kyonna ekisobola okumwaatukiriza. N'olwekyo ekimulaga ye n'gomuntu tekijja kulagibwa mu kiwandiiko kyonna ekiva mu kusoma kuno. Ebiwandiiko byonna ebikozesebwa mu kusoma kuno bijja kusibibwa mu kkabada eriko n'ekisumuluzo. Ebiggyibwa mu kukebera kuno kwonna okw'okusoma bijja kuyingizibwa mu kkomputa era bikozesebwe okuddamu ebibuuzo eby'okusoma kuno.

Ebimukwaatako eby'ekyaama bijja kukozesebwa mu kunoonyereza kwokka. Ebimukwaatako eby'ekyaama ebikunnanyizibwa mu bbanga ly'okusoma kuno tebijja kubuulirwa muntu yenna nga tetumaze kufuna lukusa kuva gy'oli.

The local Research Ethics Committee (REC) ne Uganda National Council for Science and Technology (UNCST) balina olukusa okulaba n'okufuna ebikwatagana n'okunonyereza era n'abeetabi mu buntu. **Ensasanya lw'ebivudde mu kononyereza:** Abetaabi mu kunonyereza bajja kugambibwa ebivudde mu kunonyereza n'entambula y'okunonyereza. Obubaka bwonna obunaba buzuliddwa bujja kutegezebwa abetaabi oba abasawo ababalabilira.

Okweetaba okw'ekyeyagalire: Okuyingira mu kusoma kuno kwa kyeyagalire era tewali kijja kukutuukako olw'obutabeera mu kusoma kuno. Ssinga omwanawo omuvubuka asalawo okuva mu kusoma kuno essaawa yonna olw'ensonga yonna, waddembe okukikola era kino tekijja mukosa mungeri yonna.

Obuzibu oba ebibuuzo:

Ssinga olina ebibuuzo ebirala byonna ebyekuusa ku kusoma kuno, osabiwa obukilist APFROVED Dr. Catherine Lutalo Mwesigwa

Essimu +256 772611035, Watisappu: +256 772611035 Yimeyiro: <u>dreathymwesigwa@gmail.com</u>

Dr. Maria Gorretti Nakyonyi

Essimu: +256 773288741, Watisappu: +256773288741 Yiimeyiro: mnakyonyi@gmail.com



Ssinga olina ebibuuzo byonna ebyekuusa ku kusoma kuno naye nga walyagadde okwogera n'omuntu omulala yenna atali mu kusoma kuno, osobola okutuukirira:

- Ssentebe- Dr. Paul Kutyabami, School of Health Sciences Research and Ethics Committee (MakSHSREC) Makerere University (+ 256-772404970 or +256 0200903786)
- Uganda National Council of Science and Technology,

Totekkako mukono kukiwandiko kino bwe kiba nga terina stampu ya IRB ekirizibwa, oba olunaku bweluba lwayitako

