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Full Length Research Paper

Narrative analysis on adversities in seeking oral healthcare among female caregivers of children with HIV/AIDS in a low-income setting: Voices of the women

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Abstract

It is often reported that women from low-income settings face numerous adversities in seeking healthcare, yet, their voices are often unheard. The objective of this paper is to appraise the adversities that female caregivers of children with HIV/AIDS experience in utilizing oral healthcare within the healthcare system in Nairobi City County (NCC), Kenya. The study methodology was mixed methods. Firstly, quantitative data was collected on the socio-demographic variables of 221 female caregivers attending the HIV-care facilities at three major hospitals in NCC; namely Gertrude Children's Hospital (GCH), Kenyatta National Hospital (KNH), and Mbagathi County Referral Hospital (MCRH). This was followed by qualitative data collection on first-hand accounts of the caregivers' experiences in utilizing oral healthcare for themselves and their children. The paper is founded on qualitative data as depicted in Case Narratives (CN) among the women. The findings of the narratives portrayed significant constraints and adversities suffered by the women, prevailed upon by financial constraints, limited oral health literacy, and health information and an ineffectually responsive healthcare system, lacking in purposeful and psychosocial support for the women. We concluded that contextual individual factors and innate characteristics of the healthcare system confer adversities in the utilization of oral healthcare services and caregivers' utilization of oral healthcare in NCC.

Keywords: adversities, oral healthcare utilization, female caregivers, children with HV/AIDS.

INTRODUCTION

Most African societies are considered to have holistic cultural orientations about oral health and illnesses, functions of the teeth, beliefs related to oral pain and the methods of relieving it, and distinct references to remedies for treating oral conditions within their cultural context. A painful tooth in one cultural setting may be enough to motivate care-seeking while in another, bleeding, swelling or fever may be necessary before care is sought. The cultural practices and health beliefs affect awareness, recognition and severity of illness and acceptability of service in healthcare utilization. For instance, it is reported that caregivers of children with HIV/AIDS view discolourations and break-down of teeth as resulting from the use of antiretroviral (ARV) medication, rather than a dental condition that requires medical attention (Masiga & Wandibba, 2019). The women also subscribe to the excision of 'plastic'/or 'nylon' teeth which, in their belief, causes incidences of

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diarrhea in babies, for which they seek the services of traditional healers. In some rural communities in Southern Mali, the continued preferences for traditional over modern therapies often lead to self-care, use of home remedies and consultation with traditional healers (Ellis et al., 2007). The health-seeking cultural practices among women in many African countries frequently result in delay in treatment-seeking for formal healthcare, not only for their own health, but especially for their children's illnesses (Nyamongo, 2002; Chibwana et al., 2009; Abubakar et al., 2013; Masiga & Wandibba, 2019). Notwithstanding cultural beliefs and practices, other attendant factors exist that are related to the socioeconomic status (SES) of women, largely women from low-income settings. It is well-recognized that access to healthcare, particularly dental services, remains a significant challenge among women and children of low socioeconomic status (Maybury et al., 2019; Sullivan et al., 2022).

It is stated that, in healthcare utilization, individuals formulate personal opinions and health-seeking intentions, whilst negotiating their social environment against broader structural background factors (Roura et al. 2009). These may relate to system and service factors external to the control of the individual; such as, endemic poverty, livelihood circumstances, health policies, laws and regulations, and factors relating to the healthcare system. For example, residents of rural communities may experience barriers to oral healthcare due to a high concentration of poverty, geographic isolation, lack of transportation to obtain oral healthcare, and shortages of oral healthcare providers. In addition, they are less likely to have dental insurance than their urban counterparts because they are likely to work for a small employer (Shortridge et al., 2010). Structural factors of the healthcare system are interrelated to other components that define the cost-benefit analysis of utilizing healthcare such as the distance to the health facility, financial and opportunity costs of travel, quality of care such as waiting time, attitude of providers, and ease of accessibility, all which relate to healthcare utilization patterns. Consumers of health services are bound to be sensitive to the way in which the time of utilizing healthcare is spent, with high travel distances and extended treatment times often causing reduced demand for services. We posit, therefore, that a caregiver's decision to utilize oral healthcare is a composite of their perceptions and cultural beliefs on oral health and dental illnesses, the effect of prevailing contextual societal factors, such as the innate characteristics of the accessible healthcare system.

Children with HIV/AIDS are known to suffer a preponderance of oral manifestations. In Kenya, for example, literature is rife with reports that children and adolescents with HIV/AIDS exhibit a high prevalence of dental caries and other soft tissue oral manifestations (Anver et al., 2010; Masiga & Machoki, 2012; Wang et al., 2023). It has also been determined, that these illnesses impact negatively on the quality of life of the individuals affected (Masiga & Machoki, 2013; Wang et al., 2023). Literature also reports that children with HIV/AIDS in NCC utilize oral healthcare very poorly. Seventy –one percent (71%) children attending the HIV-care facilities in NCC, were found to never having visited a dentist nor utilized any form of oral healthcare services (Masiga & Wandibba, 2017a). Much as such information abounds in literature, the real-life experiences of these women in utilizing oral healthcare is barely reported. In this paper, we seek to mitigate this paucity of information, by capturing the women's voices through a narrative analysis of their experiences in the utilization of oral healthcare within the healthcare system of Nairobi City County (NCC). Nairobi, is the capital city of Kenya. Recently, the country attained a lower-middle income status, *albeit* with inequitable wealth distribution. According to the Economic Survey of the Kenya National Bureau of Standards (2017), the low- income populace comprises households with a monthly income of KES 23, 670 and below (current rate USD 152.88). The caregivers in this study were in the lowest income population cadre, nationally, with most of their incomes falling drastically short of the recommended minimum wage for urban dwellers in Kenya (KES 13,592- 17,199: USD 87.79-111.08).

THE STUDY METHODOLOGY

We conducted a cross-sectional, hospital-based descriptive study, employing a mixed method research design that integrated both quantitative and qualitative data collection. This design enabled us to facilitate validation of data through cross-verification, as well as providing rich data sets.

Firstly, we carried out a quantitative survey among female caregivers attending the HIV-care facilities at the selected hospitals using a pre-tested survey instrument; the purpose of which was, to collect caregivers' socio-demographic data. To get the individual respondents for the survey, we did a *purposive* sampling of the women, using inclusion criteria which we determined as; (i) female adults, 18 years and above; (ii) biological or foster mothers or kin of child/children with HIV/AIDS; and (iii) female caregivers of children enrolled at GCH, KNH and MCRH HIV-care facilities. Following the survey, we collected qualitative data in the form of in-depth interviews with the caregivers, on their experiences in utilizing oral healthcare. We used, among other qualitative methods, case narratives, which form the basis of this paper. These were conducted among caregivers whom we identified as having lived with dental illness and pain by self or vicariously through their children, and were willing to

share an account on their experience in oral healthcare utilization at NCC, in the milieu of living with HIV/AIDS. Data analysis was carried out using ATLAS *ti* 8 for Windows computer software to assist in content analysis, coding and categorizing the data, following which, the findings were organized into common concepts and themes according to the information obtained. Ethical approval for the study was granted by the University of Nairobi and Kenyatta National Hospital Ethical Review Board (KNH-UON ERC- P631/10/2014). Permission to carry out the study was obtained from the various Hospital Administrators and written informed consent to participate and tape-record the narratives was attained from each individual study participant.

Sociodemographic Factors among the Caregivers

The caregivers included in the narratives were aged between 27- 71 years, while the average age of the children attending the facilities was 9.64 years (± 6.46 SD). The women personified persons of low socio-economic status that was characterized by associative correlates of low educational levels, shifting household incomes and residence in the informal settlements within NCC. Except for one caregiver who had college-level schooling, all other women had only attained primary schooling and below; accordingly, they mostly engaged in casual, non-formal employment comprising of small trades, market stalls, laundering services and the peddling of second-hand clothing and other small household commodities. The women largely subsisted on monthly household incomes of below KES10, 000 (USD 70), against which they balanced their household expenditures including healthcare expenses for which they mostly paid for, out of pocket (OPP). These women faced the common existential challenges of living in poverty, which include disparities in access to healthcare as well expounded by Peters et al. (2008).

The Case Narratives (CNs)

The following CNs are face time accounts of lived experiences generated from six female caregivers of children with HIV/AIDS. The case narratives aptly described as 'voices of the women', are reported verbatim. In the narratives, the women portray their perceptions and knowledge on dental illnesses, and delve on the anguish they suffer in the context of living with HIV/AIDS, together with their expeditions and coping mechanisms in the utilization of oral healthcare within the NCC healthcare system. Since matters of health affect individuals in different ways, the stories presented are distinctly varied, giving different perspectives of these challenges. The narratives helped us develop an understanding of the caregivers' constructs on oral illnesses, their health-seeking behavior and the constraints and adversities they endure whilst utilizing oral healthcare. The narratives were translated from Kiswahili to English without any attempt to alter the meanings or develop additional connotations to the stories. The names of the children have been hidden to protect their identities.

CN1: A caregiver of low socio-economic status whose son (and herself) suffer from dental caries and toothache. Her biggest constraint in utilizing oral healthcare is affordability of dental services, prevailed by her inability to afford health insurance.

I am 27 years old, living in Gachie with two children aged nine and three years. I look for work on a daily basis as a casual labourer. This normally involves washing clothes for people or doing any other menial work that is available. I am paid KES 200 for a day's job, while in a month I earn approximately KES 2,400-3,000. I conceived my sons when I was younger and currently they live with me and my boyfriend, although he is not the father of the boys. He is a good person and he looks after me well, but he does not work and often he takes drugs. I was once a prostitute myself and that is how I got infected with the HIV virus. The only people who know my status are my boyfriend and one of my best friends; my other family members do not know and I have no wish to tell them. My first born son is HIV-negative, but my second son is HIV-positive. I got to know his status when he was about three months old when I was advised to bring him for testing because of the illnesses that I was suffering from. When I was told that he is also infected with the virus, I was devastated and really cried. But he is not sickly himself, so he is not using the ARV medication yet. I don't see the need for him to take the medicines when he is quite okay. I think I shall tell him about his status when he is older, but for now, I am hopeful that my child will live a long life without many problems.

I know problems of teeth come about because of eating sweets and sugary foods, but I don't buy my children any such things. I mostly buy for them fruits but I think they get sweets from their friends when playing outside, or at school. In my home, everyone has their own toothbrush and we use salt to brush. We do not use toothpaste because we are not financially in a good position. Sometimes I buy toothpaste after about three months. While I was growing up, we used to have toothpaste so I know that it is good to use toothpaste, but I think it is not necessary because I can't afford it at the moment. My older son and I have many problems with our teeth. They have holes all over which become very painful at times. Some of my own teeth have been removed. I have never taken my children to visit the dentist, but I have gone there myself. I went to Kihara to see a private dentist. He said that I needed extractions,

fillings and cleaning but I could not afford his services. I found the treatment to be very expensive and that is the main reason why I have not gone back. I am planning to go to the general hospital here in Gachie, which is near my home but even there, we have to pay some money. I can tell you that I am suffering quite a bit, and I have to keep taking painkillers until I get the money to go for proper treatment. My older son also experiences toothache, and sometimes he doesn't sleep so well. It would have been very good if the government could give us free treatment for dental problems like the free treatment we get for HIV. You know treatment and medicine here (HIV-care facilities) is free and we are very happy about that. I always prefer to attend private health facilities for treatment. I admire them because they have good services and privacy. In private health facilities, the doctors are also more caring and they even ask if you have enough food unlike those in public health facilities. When you go to private dental clinics you don't waste the whole day there because their services are faster. I know that public hospitals are cheaper and sometimes they waive some fees, but because of attending to many people who come there for treatment, they only give basic care and many times they lack medicines. I don't have any health insurance because I can't afford to pay for it, but I am registered with M'Tiba which pays some of my medical bills. Mostly, I get information about health from my best friend and my pastor. I think I would also like to get more information about oral health from the hospital workers, but they don't tell us much. Surely the government should know that health is so important to a person and they should take better care of us. There are no drugs in government hospitals, and sometimes we don't have the money to go and buy them; so the government should make everything about health to be free ***(27-year-old caregiver, GCH).***

This story depicts circumstances of endemic poverty and challenges faced by the caregiver, in accessing treatment for self and children. Her son lives with pain and discomfort from toothache because she is unable to afford the cost of dental services, and she does not have health insurance. She voices a preference to utilizing oral healthcare services at private health facilities because of her perception that these institutions offer better quality of care.

CN2: This narrator exemplifies the perception among caregivers that, rather than being the disease, rotten, discoloured teeth mostly only affect self-esteem and social decorum. Despite her poor livelihood circumstances, she demonstrates a resolve to have replacement for her decayed teeth which were previously extracted due to discolourations. This was done largely to enhance her self-confidence.

I admire teeth which are white and not discoloured. When somebody has white teeth, it means that they are very clean and they can talk freely to their customers at work. According to my story, I was infected with the HIV-virus several years ago. My status was discovered when I went to deliver my last-born. Although I was not really sickly, they told me that I was HIV-positive and I was put on medication immediately. My husband is not HIV-positive. It is called a discordant relationship, but we are okay because we have been counselled on how to live together. It has not always been like this. At first it was very difficult and my husband was depressed. I thought he would leave me because of stigma but, after I started taking ARV medication and I looked the same way, he decided to stay. Not many people can tell that I have this condition. It is now eight years because that is the age of my last-born. Of my two daughters, only the second one is infected, maybe because of breastfeeding. She does not know it herself, although she was put on a low-dose of Septrin which she takes daily. I feel extremely sad when I look at her. How will I ever tell my beautiful daughter about her disease?
I have had many problems with my teeth. My gums used to swell and bleed a lot. I also had bad breath but the swelling stopped when I began taking ARV medication. The problem that remained was the discolouration of my teeth, these front teeth, which were always breaking down into small pieces. I was told that they are decayed because I used to take a lot of sweet things, but some people say that it is because of the ARV medicine that we take. Although the teeth were paining on and off, what I didn't like was the black colour and the chipping, especially because they were my front teeth. I own a hair salon and I am also a fashion designer, so you can imagine that when I talk to customers I have to cover my mouth. There is that notion that people are just looking at you and wondering why you have stayed for so long without going to a dentist. Last year, I decided to remove the black rotten teeth and have them replaced. I went to many different dentists, but their charges were ridiculous. One day a friend of mine, who had gone to a dentist in South B took me there. On the first impression when I got there, I was afraid because the dentist seemed young and very outgoing. I took some time to think about it, but I really wanted to have white teeth. I was wondering if the dentist would do a good job on my teeth, but my friend assured me that he would. He charged me KES 5,000 for the extractions, medicines, and paste to clean my teeth and also the replacement. That was when I learnt that teeth needed to be cleaned, but he did a good job. He extracted my rotten teeth, gave me medicine and asked me to use salt gurgle and go for my replacement

teeth after one week. I am very happy with my new teeth and as you can see (smiles broadly), I now smile nicely and interact with people without feeling shy. I am very keen on looking after my daughters' teeth because I don't want them to end up with bad teeth like mine, so I sometimes take them to the dentist for cleaning. Even at my salon, I don't employ girls with rotting teeth in case they frighten my customers away ***(34 -year-old caregiver, MCRH).***

Her story illustrates the perspective and value that caregivers like herself, place on the outward show of teeth. Since social interface is a daily occurrence for most of these women, being traders and small business women, the focal point of their entire mouth appears to be the appearance of the teeth, perceiving white teeth to denote cleanliness.

CN3: A foster parent who is well educated, has moderate means of living and access to health insurance. However, despite her high level of education, she has low oral health awareness and literacy and she has not given priority to oral healthcare for her nephew whom she adopted following the demise of her sister from HIV/AIDS

I have four children of my own, and I am an aunt to Isaac whom I adopted, and who is living with HIV. I am a procurement officer in one of the firms in Nairobi, where I have worked for several years since I finished college. I also own a hair salon and spa which I manage as my side-business. I came to know about Isaac's status when my sister passed away, when the boy was only eleven months old; he is now ten years old. He began taking his ARV medication when he was four years old. I bring him to the HIV-clinic here for review and follow-up once every three-four months. I find life to be quite expensive with five children to look after, but it is my responsibility to look after Isaac because my other siblings are unable to do so, and my sister was a single parent. Besides the additional financial burden of school- fees and clothing, I have to make sure that he is okay; that he is eating well and also taking his medication as required. For example, the rest of us eat a normal diet but for him, meals have to be properly balanced and we have to introduce fruits and fresh juices. Sometimes you may have food, but the child doesn't have an appetite since the drugs are too strong for him. These children are also prone to illnesses, so there are times when he goes to school and the teacher calls and tells me he is unwell. I then have to pick him from school and stay at home to monitor him.
As much as possible, I try to look after all my children's teeth. I ensure that they brush their teeth twice a day with Aquafresh toothpaste, and I am very strict with what they eat, even they know that. I only allow snacks like apples, bananas and yoghurt. Lately, I have come to discover that Isaac has some dental problems; his teeth are discoloured. I don't know the cause of this, but I think it is due to the medication that he takes, because my other children's' teeth are not very bad. I am not very sure about what to do with Isaac's teeth. Somehow, I have concentrated more on making sure that he is feeding well and that he is healthy; maybe I have neglected his teeth. I think I should wait until the teeth become painful, or until they are ready to come out. I don't have much information about oral health and how to look after the teeth. I have never thought of going to see a dentist, even for myself, unless of course there is pain. In fact, I have never seen anyone with serious dental problems so I am not very worried. Here at the HIV-care clinic, they don't teach us much about how to care for our children's teeth. They counsel us about many things, even nutrition for the children, but somehow they don't pay much attention to taking care of our teeth.
*I have also heard that it is very expensive to treat dental problems, but I can always look for money to care for my sister's son because he is like my own child now. Isaac gets free treatment at the HIV-clinic here, but when I visit the other hospitals I pay cash, or sometimes, I use my *AAR medical insurance cover. I also have an **NHIF card but that is for in-patient cover only. When my children or I are unwell, I prefer that we visit private hospitals because they have better services and follow-up. Private clinics also open on Saturdays which is convenient for me because I don't go to work on that day and the children also don't go to school. Public hospitals may be cheaper, but the health workers there don't give you much attention; instead, they make one feel like they are doing one a favour. This always annoys me so much* ***(42 -year-old caregiver, GCH).***

*Africa Air Rescue medical insurance cover
**NHIF- National Health Insurance Fund

The narrator's story presents an account of being affected by HIV/AIDS through caring for a nephew who suffers from the affliction. She addresses the challenges that she faces in caring for an orphaned child with a chronic medical condition. While she narrates on how well she takes care of him, she is lacking in dental awareness and the need to utilize oral healthcare. Poor oral health literacy (OHL) was a common finding with most of the caregivers, together with their healthcare providers at the HIV-care facilities.

CN4: A grandmother who is a caregiver to her grandchild who lost her own mother from complications of HIV/AIDS. She has previously taken her grandchild to visit a dentist when the child was teething but later, she resorted to using

home remedies and other age-old methods that she considered had been successful with her own children.

I live in Kibera with my last-born son who is in Form two and my granddaughter who is two years old. She belongs to my daughter who passed away about one year ago. It was a very difficult time for me. I had observed my daughter ailing for some time, and as a mother, I suspected that she has 'that bad' illness, but I didn't know how to approach it. I am not sure if she suspected it herself. In 2014 when she became pregnant, she looked a little better and I thought that she had started taking medication but soon after she gave birth, she confessed to me that her baby was infected with the HIV virus. Looking back, I think this was she first time she herself, knew about her own status. She was completely devastated and from that time, she became depressed and grew progressively weak and she died even before her daughter was one year-old. This is my daughter's only child and I decided to take care of her since I am still physically strong. The child's father wanted her but I refused, because he doesn't even have a job and he lives in the village; he cannot take care of my granddaughter. I am a widow myself, my husband having died from cancer about 15 years ago. My own plans have changed. I was waiting for my son to finish Form Four (High School), then I would relocate back to the village, but as you can see, I am left with the burden of educating and caring for my grandchild. I sell second-hand clothes at Adams Arcade and earn between KES 5,000 and 10,000 a month.
My granddaughter recently suffered from fever and diarrhea but I know that was because of teething. I saw it with my own children. When I took my grandchild to the clinic, the doctor told me that perhaps the baby had another infection, or she had eaten something that affected her. I didn't believe him because I had seen it with my own children. That is when I remembered that I used to rub my children's gums with a powder which I get from the village; that, relieves the discomfort of teething and reduces the diarrhoea. I did the same with my grandchild and she is now okay. Sometimes children develop teeth with worms inside, which makes the child extremely ill. These teeth have to be removed by women who are specialists. I have not started brushing my granddaughter's teeth because a child who brushes their teeth too early can destroy their milk teeth which are very delicate. I don't see why someone has to go to the dentist all the time. Sometimes you can just use salty water and the problem goes away. For my granddaughter's milk teeth, I will remove them myself when they are ready. That is the best way, and it is what I did with my own children. I fear going to private hospitals because they are very expensive. I prefer government hospitals. They are affordable and treatment there is better since they have doctors specialized in different illnesses. I have NHIF for which I pay KES 500 monthly, but it only covers me and my son, not my granddaughter. My problem with NHIF is that when you are admitted, they pay for your bed charges only and not for the medicines or any other treatment. Luckily, for my granddaughter's condition, I get free treatment here at the HIV-care clinic, but for her other medical expenses I ask my older children to help, although their own jobs are not very well-paying ***(65-year-old caregiver, KNH).***

In spite of being of elderly age, this grandmother finds herself thrust into the precarious position of 'parenting' a grandchild who has been orphaned by the death of her own daughter from ravages of HIV/AIDS. As depicted by this narration, older caregivers are more inclined to using alternative remedies linked to age-old traditions that they have practiced in the past with their own children.

CN5: A woman living with HIV/AIDS who suffers from dental caries and cancer of the oral cavity. Her 2-year-old son is also infected with HIV. Her husband has disowned the family. Given her life circumstances, she is unable to afford any healthcare and/or treatment for her oral cancer. She largely depends on well-wishers and charitable organizations both for her up-keep and medical expenses.

I knew of my HIV-positive status about 8 years ago. My new-born son was quite sickly and not growing well. By the time he was one year old, he weighed only about 6 kilogrames. My neighbours must have suspected my condition because they advised me to bring my child here to the HIV-clinic at Getrudes Hospital. He was discovered to be HIV-positive. He was then admitted and started on treatment. Unfortunately my older son who is ten years old and myself were also found to have the virus, but my eldest daughter whom I gave birth to when I was still in school is free from the disease. When my husband got to know about it, he became so angry and threw me and my children out of the house in the middle of the night. Can you imagine that? He refused to go for testing himself. To make matters worse, my own mother and my brothers and sisters have disowned me and, up to now, we have no association. If it were not for the caring attitude of the staff at this clinic, I would not have been able to cope and I don't know where I would have been today. Here, they counsel me and even help me financially to be where I am. I can tell you, when this journey of mine started, I was in a very bad shape.
About one and a half years ago, I experienced some dental pain due to cavities in my teeth but, having no

money to attend for treatment, I kept on buying painkillers to help me sleep at night. The pain subsided but soon after that, my gums began to swell. My tongue also had a swelling. I would keep poking the swelling with a toothpick and wash my mouth with salty water. One time I told the doctor at the clinic here, about the swelling on my tongue and she referred me to Kenyatta National Hospital (KNH). I did not have transport because I live in Gachie and KNH is very far. I was lucky that the social worker gave me some money for fare. At the hospital, I was told to go back for a 'biopsy' of the swelling on my tongue. I did not have my painful tooth removed because I didn't have the money to pay for it. When I went for my results, I was told that I have cancer of the mouth. It was shocking to me. I had surgery done to remove the swelling, and was told that I needed chemotherapy and radiotherapy. I have not done that because of several reasons. Firstly, I have to wait for my turn on the waiting list which is already very long and, secondly, I don't have money for the treatment or fare to keep going to the hospital. At KNH, they don't consider your social circumstances and whether you can afford the treatment or not. I hear that you can bribe the doctor with KES 50,000, but I don't know if that is true. Where would I get that money anyway? A few months ago, the cancer moved to my eyes, and one of my eyes became completely blind. I was lucky to be operated on the other eye free of charge at Lions Eye clinic, so I am left with one good eye. For the cancer of the mouth, sometimes I go back to KNH and they prescribe me medicines which I come to collect here at this clinic when they are available. It is a difficult life but that is how I live with my cancer. My older son who has HIV also suffers from teeth problems but currently I have taken him to 'ushago' (village) to live with his grandmother, the mother of my former husband, because I can't cope with looking after him here. I don't know how he is getting on, but I hope they are reminding him to take his medicines so that his condition doesn't get worse. I have now joined a cancer-support group called 'Ladies Hope', which has made a big difference to my life. When we go for meetings, we are happy because they encourage us to live positively with cancer. They also donate clothes and help us with some money to attend hospital when we have appointments. The best thing is that they train us to make handicrafts for sale in order to make a living; you can see these scarves and mats that I have made which I sell to my neighbours and friends. "Here, you can try one" (ties one of the scarves around my neck). I don't know why the government does not help us to get medical care more easily; we are really suffering, some of us who can barely afford to eat properly, leave alone getting treatment when we are sick ***(37-year-old caregiver, GCH).***

The narrator suffers chronic dental pain from rotten teeth and cancer of the oral cavity. She is sickly and cannot do much to improve her life circumstances and /or access timely healthcare. Her story embodies individual and structural barriers that women of her socioeconomic status face in utilizing oral healthcare. The higher-tiers of the healthcare system only gives her additional challenges of long commute and transport charges, in addition to a long list of patients seeking similar specialized healthcare.

CN6: A second grandmother who is the primary caregiver to an eleven-year-old child with HIV/AIDS, abandoned in her care. The grandchild has developed cancer of the oral cavity following a small swelling in her mouth which the grandmother largely ignored until the child was quite ill. She is currently undergoing chemotherapy at KNH. Her grandmother has been forced to relocate to Nairobi so that Christine can access care.

I am the grandmother of an 11 year-old-child. I have been looking after her since she was four years old, when my daughter brought her home and left her with me then went back to Nairobi. I knew that she had a child but she had never brought the child to see me before. It is only later that I learnt that my daughter is sick, and also the baby. I think the reason she left the baby with me is because this disease (we call it 'chira') has a lot of shame associated with it. Anyway, I took care of the baby and she was doing well, until she was about eight years old when she developed a swelling on the right side of her jaws. I didn't take it seriously at first, because when I looked at her teeth, they were okay. But later on the swelling continued and she also developed some 'vidonda' (lesions) inside her mouth. Getting dental care in the village is very difficult because dentists are very few and you have to travel very far to get one. I tried to use our traditional medicines, but it wasn't working very well so, later, I was advised to take her to Kenyatta Hospital. It took a bit of time for me to get enough money, but the child's cousin who lives in Nairobi assisted me and later we travelled to Nairobi with the sick child. The cousin took us to Kenyatta National Hospital (KNH) for what they called 'biopsy'. When the results came out, it shocked us because we were told that the child has cancer of the mouth because of AIDS. Surely, how can AIDS give you cancer in the mouth? I decided to relocate from home which is in Homa Bay and come to Nairobi so that my grand-daughter could get the right treatment, but it has taken too long. Imagine, I have been in Nairobi since November last year (2 years), and she only started chemotherapy recently! It is very depressing that this child has suffered so much. She spends so much time at the hospital that she can't even

attend school properly. Sometimes she is too weak to have the chemotherapy and they have to add blood and then wait for her to get better before they start again. It has been in and out of the hospital for my poor granddaughter.
I face many challenges myself. Having relocated to Nairobi, I now have to put up with my late brother's daughter who fortunately, helps me to take my grand-daughter to the hospital. You can see that I am quite old and not so strong myself. Money is also a problem and I have to do some tedious work here and there, like washing clothes, to get a few shillings to ensure that she eats properly. The child's mother is alive and lives in Nairobi, but I don't know where she stays. Even now that I am here and the child is undergoing treatment, I cannot tell you where my daughter is, or what she is doing but, occasionally, she sends me money for upkeep and medicine for the child. The other thing, I have to remember is to give her the HIV medicines which I get from the clinic, every single day; the doctors have told me that perhaps, I used to forget to give her the medicines when we were at home in Homa Bay, and that is why she became very sick and got cancer in the mouth. They had to change and give her stronger medicines, but I shall be more careful now. I believe that God has His own plans for this child and, therefore, I leave her in the hands of God ***(71-year-old caregiver, KNH)****.*

This is an aged woman caring for a child suffering from the adversities of a chronic medical condition that was not diagnosed and managed in a timely manner. In spite of her advanced age of 71 years, she has had to leave her rural home and delocalize to Nairobi to seek advanced treatment for her grandchild at Kenyatta National Hospital. She did not seek oral healthcare when her granddaughter first suffered from swellings of the jaws and oral cavity, partly out of ignorance and partly because of lack of access to oral health providers at her rural home. She is also struggling with a disease she knows very little about.

DISCUSSION

The narratives yield rich qualitative data on caregiver's perceptions and knowledge of oral health, the pain and suffering caused by oral illnesses that occur in the context of HIV/AIDS, and the constraints and adversities that they face in seeking and utilizing oral healthcare, including their coping strategies. We hypothesize that, despite the psychosocial circumstances of the women being very different, they face common challenges within the complexities of the circumstances in which they find themselves.
Among the narratives we report, one caregiver, CN2, has the cognition that the outward show of teeth which are white and well aligned, is akin to good oral health. In her view, it impacts on positive self-esteem and social interaction. For this particular woman, concern for aesthetic appearance was the sole reason for visiting the dentist.
The narratives also suggest that decisions on whether to comply with a recommended treatment regimen or engage in self-care, could have a cultural overbearing despite the urban dwelling of most of the women, particularly so, the older caregivers, who used home remedies as first-aid measures to relieve toothache and gum swelling. In the CN4 narration, the grandmother-caregiver, despite the advice of a medical doctor, favoured treating illness symptoms with the use of traditional methods.
The use of traditional oral health practices in and of itself, is reported in many cultures in the African region. For instance, Ngilisho et al. (1994), reports that patients in Tanzania commonly seek oral healthcare from traditional healers despite the establishment of modern emergency oral healthcare services in their communities. The reason for this may be, as stated by Nyamongo (2002) that; when health services are inadequate and not affordable to people who need them, other factors such as existing cultural beliefs and practices can lead them to turn to the use of home remedies while others may choose to use traditional healers. Given the socioeconomic backgrounds of the women in this study, the use of traditional methods is likely exacerbated by the perceived prohibitive costs of formal oral healthcare services (CNs1&3). The women who utilized traditional methods were seemingly socialized to believe in them as being safe and effective since the remedies had been successfully passed on generationally. That the use of cultural remedies and/or self-care measures ultimately causes a delay in utilizing formal healthcare is consistent with the observations reported by McGrath (2005).
We noted that grandmothers were an identifiable category in primary care-giving of children with HIV/AIDS, forming two-fifths of the CNs. In both situations, CN4 and CN6 respectively, the grandmothers were forced to step in and raise orphans left behind, or abandoned as a result of sickness and death from HIV/AIDS. This likely reflects the present-day scenario of the negative social effects of HIV/AIDS that leave orphaned children in the care of elderly grandparents- grandmothers- in particular. In most African societies, the sense of duty and responsibility of extended families towards orphaned children is almost without limits and forms the basis for the assertion that 'traditionally, there was no such thing as an orphan in Africa' (Foster, 2000). This kinship is illustrated in the case narratives involving grandmothers CN4 and CN6 and an aunt, CN3. However, the unforeseen responsibilities strain elderly caregivers who are already weighed down with physical ageing, and financial struggles.

Nyambedha *et al.* (2013) report that the main problems faced by caregivers of orphaned children in Western Kenya are lack of food, school fees and poor access to medical care; while extended families embrace the physical, emotional and spiritual needs of orphaned children as well as providing them with food, clothing and shelter, the utilization of oral healthcare is given a lower priority due to financial constraints in low-income families. It was apparent from the narratives that grandmothers make enormous sacrifices against all odds, to care for their grandchildren, but the financial strain is audible. Further, they face challenges in meeting the children's medical needs in the context of a disease they know very little about, such as, the need for strict adherence to time in dispensing ARV medication. In narration CN6, there are additional physical and emotional strains on an elderly caregiver who, involuntarily, has to interrupt her normal rural life and relocate to a new environment and lifestyle in order to access oral healthcare for her granddaughter.

The perceptions on health do not only depend on one's sensitivity to signs and symptoms of disease, but are also influenced by one's health knowledge. Health literacy (HL) is being increasingly recognized as an important factor in influencing the utilization of healthcare. It is defined as the degree to which an individual has the capacity to obtain, process and understand basic health information in order to make appropriate health decisions. Vann *et al.* (2010) examined the impact of oral health literacy (OHL) among female caregivers in northern Carolina, United States, and reported a positive link between caregivers' low level of oral literacy and poorer oral health outcomes. In the narratives outlined in this paper, the OHL had poor reflection in almost all the CNs. For instance, in CN3, the caregiver is a woman of sound education, moderate means and access to health insurance but she is not cognizant of the need to utilize oral healthcare services for the children under her care. The children with HIV/AIDS in CNs 5 & 6 accordingly, suffer far-reaching consequences that greatly reduce their quality of life due to poor oral health information. It was clear that caregivers have very little information on the potential co-morbidities of HIV/AIDS; for instance, one narrator (CN6) is unable to make the connection between the illnesses in the oral cavity with the medical condition that exists in her granddaughter. She, (grandmother) asks, *'how can having HIV/AIDS cause you to have cancer of the mouth?'*

Almost all the narratives depict lack of financial enablement among the women for the timely utilization of oral healthcare- there is portrayal of woeful living and lack of ready resources to meet their daily needs, leave alone access to oral healthcare. Ha *et al.* (2002), states that a high expenditure on healthcare exerts unplanned financial burden on individual families. The financial strain depicted in CNs 4, 5 & 6 causes these women to seek alternative sources of welfare and/ or resort to extra menial work to facilitate oral healthcare services, whilst the children put up with severe oral pain and discomfort. In the process, their dental illnesses become muddied and complicated making it more difficult and expensive to manage.

Health insurance is one of the most important predictors of healthcare utilization; those with dental insurance being found to be less likely to report unmet needs and delayed visits for oral healthcare (Yu et al., 2002: Kenny et al., 2005). Uninsured women are found to face larger access barriers and utilize fewer health services, especially preventive services (Almeida et al., 2001). Notwithstanding other factors, having health insurance would be expected to impose a mediating effect in access to oral health services for these children. However, investing in health insurance is typically dependent on having a regular source of income, which is unlikely in this cohort of women. In a previous study, more than two-thirds (68%) of caregivers did not have any form of health insurance (Masiga & Simiyu 2017b); instead, they relied on OOP expenditure for healthcare. The lack of health insurance exposes a limitation in safety net to cushion the women against the high costs of consuming oral healthcare within the healthcare system of NCC.

Patient satisfaction with non-medical aspects of care is likely associated with better compliance with treatment instructions, prompt seeking of healthcare and a better understanding and retention of medical information Frequently, patients will base their satisfaction of quality of care on the promptness in which they receive care, a clean hospital environment and pleasant healthcare workers who treat patients with respect, rather than the technical quality of the health services. The confines–of such structural factors in NCC healthcare system is well underscored in the narratives. Narrators CN1 & CN4 allude to preferences in consuming oral healthcare at private institutions, which they perceive to have better organization and service delivery; *albeit* the high cost of care, which deters them from utilizing these facilities. Likewise, in order to attain specialized oral healthcare, narrators CN5 & CN 6 sought enhanced oral healthcare at higher-tier government hospitals; yet, they allude to several challenges that seemingly constitute structural barriers to accessing the care that they require. They narrate the strenuous trips to the hospitals and encounters of long waiting lists and delayed appointments; in addition, they have transport burdens that come with long-distance travel to the health centers. Further, in CN6, the caregiver (grandmother) makes reference to the disparities in urban vs rural qualities of oral healthcare. Her narrative submits that rural communities experience geographic isolation in oral healthcare with fewer oral health professionals and

facilities. This unfortunate misdistribution of the oral health workforce in Kenya is amplified in a report by Okumu *et al* (2022). In this instance, the caregiver is forced to delocalize from her rural home to urban Nairobi to enable her meet the healthcare needs of her grandchild. We suggest that structural factors in NCC distinctly contribute to adversities in the utilization of oral healthcare for female caregivers of children with HIV/AIDS.

The emotional and psychological impact of these challenges may not be ignored. There were several reasons that could be used to confer Serious Psychological Distress (SPD) among the women. Throughout the narratives, there is woeful cry of insufficient funds to access timely and preferred dental services, whilst other anxieties arose from lack of health information, insurance coverage, separation from family, long waiting lists at high-tier hospitals necessitating multiple re-visits, delocalization to seek better healthcare and uptake of new responsibilities, especially among the elderly caregivers, and in general, limitations in the ability to work and partake Activities of Daily Living (ADL). Further, there is shock, tears and devastation related to the stigma of HIV/AIDS, for which, there is no clear evidence of psycho-social support from the healthcare system, other than some empathy from health providers at the HIV-facilities. Nonetheless, the women demonstrate stoic and resilience to carry on. Their coping strategies include certain trade-offs, such as utilizing the nearest subsidized government facilities to save on transport and service fees and, oftentimes, enduring the long waiting times and travel distances to the health facilities. In addition, they seek welfare from well-wishers and charitable organizations for upkeep and medical expenses. The drawback is that they utilize dental services only when pain became insufferable and/or when HIV/AIDS co-morbidities became unbearable which was almost always the case. Dismuke & Egede (2022) associated an increased healthcare expenditure and healthcare utilization across multiple health categories among adults with SPD in the United States *excepting* for dental services where expenditure and dental visits were greatly lowered, similarly in this study.

CONCLUSION

The main conclusions of the study, from the voices of the women, are that low-income caregivers of children with HIV/AIDS in NCC face significant constraints and adversities that contribute to deprived utilization of oral healthcare; with compounding factors being, financial limitations, cultural undertones among the older women, poor oral health literacy(OHL) with little information on dental illnesses and their co-morbidity with HIV/AIDS, and a healthcare system that is ineffectively responsive to their oral health and psychological needs. This study has implications for oral health policy and practice. The oral cavity, being a constituent of the body where HIV/AIDS co-morbidities predominate, there is need for targeted interventions and policies that essentially reduce social disparities and oral health utilization within the broader healthcare system, more so, for women and children from low socioeconomic settings. We suggest that future research in this area should seek policies that include dental services within the framework of *free* comprehensive healthcare at the HIV-facilities, and should include intensification of oral health education and preventive measures within the context of caregivers' cultural construction, in order to afford betterment of overall health outcomes for children with HIV/AIDS.

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