

**DETERMINANTS OF THE UTILIZATION OF ORAL HEALTHCARE AMONG
FEMALE CAREGIVERS OF CHILDREN WITH HIV/AIDS IN NAIROBI CITY
COUNTY, KENYA**

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DECLARATION

This thesis is my original work and has not been presented for a degree in any other university.

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This thesis has been submitted for examination with my approval as University Supervisor.

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DEDICATION

To my late parents, Mzee Zakayo Onyango Ogola and Mama Agnes Wairimu Onyango for nurturing the love of education and for their foresight and dedication in ensuring their children get the best possible start in their academic journey.

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ABSTRACT

This thesis presents the findings of a study on determinants of the utilization of oral healthcare among caregivers of children with HIV/AIDS in Nairobi City County. The central problem of the study were the issues associated with the utilization of oral healthcare for children with HIV/AIDS, who suffer a preponderance of oral manifestations, and whose need for oral healthcare may be greater than the general population. The study was concerned that, despite the problem of high prevalence of dental caries being noted among children with HIV/AIDS, for a variety of reasons, these children continue to face limited access to oral healthcare. The general objective of the study, therefore, was to explore the ways in which individual and societal factors influence female caregivers in utilizing oral healthcare for children with HIV/AIDS in Nairobi City County. Specifically, the study sought to determine the influence of caregivers' oral health perceptions and cultural beliefs, the impact of socioeconomic factors, and the significance of structural factors in the utilization of oral healthcare. The study was guided by the health services utilization model.

The study was hospital-based and was both exploratory and cross-sectional by design. It was carried out among 221 female caregivers of children with HIV/AIDS attending the HIV-care clinics at Getrude Children's Hospital, Kenyatta National Hospital, and Mbagathi County Referral Hospital. The findings of the study indicate that, one, caregivers have prevailing perceptions and cultural beliefs about oral health and illness management which are holistic and woven into the social and cultural fabric of their daily lives and influence the utilization of oral healthcare. Two, the socio-economic circumstances of the caregivers such as low income levels and lack of social health insurance have a compounding effect on the low utilization of oral healthcare for children with HIV/AIDS. Finally, structural factors and characteristics of the healthcare system are significant in selecting an oral health provider; caregivers weigh out cheaper options on user-costs and prices of care, geographic service location, health workers attitudes, and waiting time at the respective health facility.

It can, therefore, be concluded that a caregiver's decision to utilize oral healthcare is a composite of perceptions and cultural beliefs on oral health and dental illnesses, effect of contextual societal factors, and innate characteristics of the healthcare system. The study found that caregiver's measures of oral health needs are based on individual conceptions of oral health and perceptions of severity of disease and this is threatened by limited oral health literacy and lack of basic oral health information. Additionally, the caregivers perceive the cost of services and access to oral healthcare to be prohibitive and this, coupled with low enrollment with social health insurance, constitutes major barriers to the timely utilization of oral healthcare for children with HIV/AIDS.

The study, therefore, recommends that, one, the National government considers greater subsidy on social health insurance for low-income earners and pro-poor payments, to enable those in the informal sector with irregular incomes benefit from public health insurance. Two, the County government establishes satellite dental health facilities closer to the people to reduce the distances of travel to regulated oral healthcare providers. Finally, there is need for collaborative research and development of innovative models that support oral health services for children with HIV/AIDS within the context of their caregivers' cultural construction and comprehensive healthcare.

ACRONYMS AND ABBREVIATIONS

| | |
|-------------|---|
| AAPD | American Academy of Pediatric Dentistry |
| AIDS | Acquired Immunodeficiency Syndrome |
| ARV | Antiretroviral therapy |
| CDC | Centre for Disease Control |
| ECC | Early Childhood Caries |
| ERC | Ethical Review Committee |
| FBOs | Faith Based Organizations |
| FGDs | Focus Group Discussions |
| GCH | Gertrude Children's Hospital |
| CDC | Centers for Diseases Control |
| GIS-SECTION | Geospatial Section |
| GNMR | Greater Nairobi Metropolitan Region |
| HIV | Human immunodeficiency virus |
| IDH | Infectious Diseases Hospital |
| IOM | Infant Oral Mutilation |
| KIIs | Key informant interviews |
| KNH | Kenyatta National Hospital |
| MCRH | Mbagathi County Referral Hospital |
| MTC | Medical Training College |
| NC | Nairobi City |
| NCC | Nairobi City County |
| NGOs | Non-Governmental Organizations |
| NHIF | National Hospital Insurance Fund |

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|---------|--|
| NGOs | Non-Governmental Organizations |
| OHL | Oral Health Literacy |
| OHS | Oral Health Status |
| OHE | Oral Health Education |
| OH-QoL | Oral Health-related Quality of Life |
| OOP | Out-of-Pocket |
| PACT | Partnership for Advanced Care and Treatment |
| PEPFAR | President's Emergency Plan for AIDS Relief |
| PMTCT | Prevention of Mother to Child Transmission |
| PLWA | People living with HIV/AIDS |
| SDS | School of Dental Sciences |
| SES | Socio-economic Status |
| SHI | Social Health Insurance |
| SSC | Sunshine Smiles Clinic |
| SPSS | Statistical Package for the Social Sciences |
| STDs | Sexually Transmitted Diseases |
| USAID | United States Agency for International Development |
| UoN | University of Nairobi |
| UoN-SDS | University of Nairobi-School of Dental Sciences |
| VCT | Voluntary Counseling and Testing |

CHAPTER ONE

BACKGROUND TO THE STUDY

The mouth is a mirror of health or disease occurring in the rest of the body, in part because a thorough oral examination can detect signs of numerous general health problems such as nutritional deficiencies and systemic diseases including microbial infections, immune disorders, injuries and some cancers (US Department of Health and Human Services, 2000).

1.1 Introduction

Oral health is essential for the general health and well-being of individuals and the population; the mouth is both a cause and a reflection of individual and population health and well-being. Illnesses of the oral cavity can compromise a person's well-being particularly in situations where they cause pain on eating. Poor oral health affects systemic health such as nutritional status, growth and function, speech, and social development with consequences that can seriously compromise quality of life (US Department of Health and Human Services, 2000:43). For people suffering from dental, oral or craniofacial diseases, the link between oral health and general health and well-being is beyond dispute. If mouth pain or tenderness makes it difficult to chew or swallow, or if one cannot taste food as one used to, one may not eat enough and this could impact on one's nutritional status and well-being. Several other types of morbidity (both individual and societal) have been associated with poor oral health particularly among children, including chronic pain, loss of days from school (Gift et al., 1992:1667) and inappropriate use of emergency departments (Cohen et al., 2002: 720). In a rare case, an untreated oral disease in children has led to death (Hibbard and Nguyen, 2012:78). Despite these manifestations, oral health disparities

persist in many populations because of a web of influences that include complex cultural and societal processes that affect both oral health and access to effective dental healthcare.

Globally, the greatest burden of oral diseases is on the disadvantaged or poor population groups (Petersen et al., 2005: 661). The current patterns of oral diseases reflect distinct risk profiles across countries, which are related to living conditions, lifestyles and environmental factors (Petersen et al., 2005: 665). For example, over the last decades an overall decrease in dental caries among children has taken place in several high income countries, most likely the result of a combination of factors such as better oral health behaviour, an improvement in living conditions, widespread use of fluoride and the establishment of prevention-oriented school health programmes (Marthalar et al., 1996:249; Downer et al., 2005:91). However, even among these populations the dental health of the less well-off is worse than the rest of the population (Whelton *et al.*, 2004:42). The opposite trend is noted among low-income countries where increase in the incidence of dental caries is thought to be the result of a complicated causal web related to the economic, demographic and dietary transitions, low tradition of oral healthcare, limited use of fluoride, and lack of oral health services (Petersen and Lennon, 2004: 320; Sheiham, 1984: 145).

In many countries across the world, significant proportions of children (and adults) are underserved, or not adequately targeted by preventive and oral health promotion measures in the context of public health programmes (Kwan and Petersen, 2010: 172). Many countries in Africa, Asia and Latin America have a shortfall of oral health personnel, and the capacity of the health systems is generally limited to pain relief and emergency care with little, if any, importance given to preventive or restorative dental care. In Africa, for example, the average dentist to population ratio is approximately 1:150,000, compared with about 1:2000 in most industrialized

countries (Petersen et al., 2005:663). The availability and accessibility of oral health services are, therefore, seriously constrained and provision of essential oral healthcare is limited; reports from the region show very low utilization of oral health care services, and visits to dental care facilities are mostly undertaken for symptomatic reasons (Varennee et al., 2006:164). Among children and adults suffering from severe tooth decay, teeth are often left untreated or are extracted to relieve pain or discomfort. Therefore, according to Petersen et al. (2005:665), public health problems related to tooth loss and impaired oral function are expected to increase in many developing countries.

1.2 Societal determinants of healthcare utilization

Much research has examined individual biologic/physiologic contributions to children's oral health as the primary focus of study. However, less is known about the broader social and cultural determinants of oral health and how different contexts of care interact to influence health-seeking behaviour and oral healthcare utilization. It is often said that the demand-side determinants of health-care utilization are complex and difficult to assess, being conceptualized as multidimensional constructs consisting of pragmatics, health knowledge and beliefs, expectations about care, skills and marginalization (Seid *et al.*, 2004:329). Behavioural scientists have attempted to explain individual behaviour as a function of characteristics of the individual himself or herself, characteristics of the environment in which he or she lives and/or some interaction of these individuals with societal forces (Moore, 1969, cited in Andersen and Newman, 1973:3). Whether and where to go for treatment starts well before arrival in a health facility and requires a myriad of complex, and potentially confusing considerations to be made by the individual. Societal determinants of utilization are further shown to affect individual determinants both

directly and through the responsiveness of the health system (Andersen and Newman, 1973:3). Children live in families and families are included in communities, which come into existence because of socially determined differences in opportunity, behaviours, culture, beliefs and exposure to myriads of other factors. Family characteristics result in part from individual beliefs or actions and in part from the family's affiliation with a specific population group, its social position in the local community and ability to access resources. How exactly societal contexts combine to prevent children from timely utilization of oral healthcare and to create unmet treatment needs warrants further theoretical as well as empirical investigation. The characteristics of specific communities, civic services and resources available, healthcare financing mechanisms, and workings of the public healthcare system constitute contexts which all directly or indirectly affect healthcare utilization (Barkar and Horton, 2008:10). This study sought to examine the individual and societal contexts among a cohort of female caregivers, which affect the utilization of oral healthcare for children with HIV/AIDS.

1.3 Oral health and HIV/AIDS

Acquired Immunodeficiency Syndrome (AIDS) is a chronic, potentially life-threatening condition caused by the Human Immunodeficiency Virus (HIV). HIV interferes with the body's ability to fight the organisms that cause various diseases by damaging the immune system, thus exposing the body to numerous potentially fatal infections. Several studies have demonstrated that having HIV-infection has a negative impact on oral health (Enwonwu, 1995: 544; Arendorf *et al.*, 1998:178; Greenspan and Greenspan, 2002:38; Holmes and Stephen, 2002:42). Approximately 40-50% of people who are HIV-positive have oral disease caused by fungal, bacterial or viral infections that often occur early in the course of the disease; in fact, oral manifestations are among the earliest and most important indicators of infection with HIV. In cases where a person's

HIV status is unknown, the presence of these lesions provides a strong indication of having HIV-infection both in children and adults (Ramos-Gomez *et al.*, 2000:10; Coogan *et al.*, 2005:700).

The commonly occurring oro-facial lesions among children with HIV/AIDS include oral candidiasis, herpes simplex infection, linear gingival erythema, bilateral parotid enlargement, and recurrent oral ulcerations (Ramos-Gomez *et al.*, 1999:85a; Chen *et al.*, 2003). The prevalence of these lesions, however, may vary from region to region, for instance, studies have also reported an increase in the number of HIV-infected children presenting with cancrum oris in Africa (Chidzongza, 1996: 59; Adedoja, 2002:500; Naidoo and Chikte, 2004:15). Little is known of the prognostic implications of oral lesions in short and long-term survival in resource-poor countries, nonetheless, it is often recognized that the need for oral healthcare including immediate care and referral, treatment of manifest oral disease, prevention of oral health problems and health promotion is particularly greater for those infected with HIV/AIDS to alleviate symptoms associated with opportunistic infections (Ramos-Gomez *et al.*, 2000:10) and equally, for those from the underserved and disadvantaged populations of developing countries (Schmidt-Westhausen *et al.*, 2000:339). A body of evidence from both developed and developing countries further indicate that children with HIV/AIDS manifest a high prevalence of dental caries (Howell *et al.*, 1992:370; Valdez *et al.*, 1994:116; Madigan *et al.*, 1996:131; Hicks *et al.*, 2000: 360; Pongsiriwet *et al.*, 2003:184; Anver *et al.*, 2009:95). The severity of dental caries, according to some researchers, increases with advanced HIV/AIDS disease and immunosuppression (Beena, 2011:89; Hicks *et al.*, 2000:362). In the United Kingdom, these children were further reported to come from socioeconomically disadvantaged racial minorities who are already a high risk group of caries acquisition and poor dental attendance (Eldridge and Gallagher, 2000:23).

Dental caries is a localized progressively destructive disease of the teeth that leads to demineralization of the organic components of the tooth structure. The burden of dental caries is multifaceted. The disease can be severe and have far-reaching effects in children, for example, the consequences of early childhood caries (ECC) has been associated with a higher risk of new carious lesions in the permanent dentition (O'Sullivan and Timanoff, 1996:82; Al-shahan *et al.*, 1997:39), hospitalizations and emergency room visits (Fleming *et al.*, 1991:28; Shwartz, 1994:966; Sheller *et al.*, 1997:473), increased treatment cost and time (Griffin *et al.*, 2000:25; Ramoz-Gomez *et al.*, 1996:110), delayed or insufficient physical development especially in the child's height and/or weight (Acs *et al.*, 1992:304; Ayhan *et al.*, 1996:2011), loss of school days and increased days with restricted activity (Reisine, 1985:29; Gift *et al.* 1992:1667), and diminished ability to learn (Ramaj, 2000:16). More recently, research has demonstrated the impact of severe dental caries on a child's quality of life in terms of the child's well-being (Low *et al.*, 1999:326; Acs *et al.*, 2001:421).

A number of factors conspire to disrupt the equilibrium between demineralization and remineralization of the dentition among children with HIV/AIDS. These children often require dietary supplementation due to failure to thrive (FTT). The high carbohydrate supplements represent a frequent source of refined substrate whose ingestion causes prolonged drops in salivary pH, thereby promoting demineralization of teeth. Children with HIV/AIDS are also regularly required to take medicines on a long-time basis in the course of therapy. The medicine used among the younger children is syrupy, often sweetened to improve compliance. The frequent exposure to sweetened medicines contributes to increased risk of ECC among children with HIV-infection (Eldridge and Gallagher, 2000: 24; Kenny and Somaya, 1989:45). Some of the medicines may also negatively affect salivary flow and alter the nature of oral flora. The reduced

salivary flow and subsequent diminished buffering capacity further increases the risk of developing ECC particularly, when other etiological risk factors exist such as night-time bottle feeding and poor oral hygiene.

1.4 Statement of the problem

Treatment modalities for HIV infection have consistently improved the life expectancy of children with perinatally-acquired HIV infection, and delayed the onset of debilitating illnesses. It is now common for these children to survive into adolescence and adulthood. However, having HIV/AIDS increases one's risk of oral health problems (Patton, 2000: 186). Many of these problems arise because the person's immune system is weakened and they are less able to fight infection. In Kenya, for example, the prevalence of dental caries among children and adolescents with HIV/AIDS is high, ranging from 65-84.4 % (Anver *et al.*, 2009:3; Masiga and Machoki, 2012:210). More recently, the prevalence of gingivitis among a cohort of children living with HIV/AIDS was reported to be 86.5% (Hussein and Opinya, 2017:6). As the survival rates of these children increases and as their early years become less filled with calamitous illnesses, they are increasingly likely to mirror their societal counterparts in their everyday lives. However, with regard to oral health they are more likely to have decay in their dentition than their unaffected siblings (Madigan *et al.*, 1996:135); they are less likely to be caries-free and more likely to have an increased burden of oral health.

Despite reports that children with HIV/AIDS suffer from dental pain (Howell *et al.*, 1992:370), and the clear indication of unmet oral health needs among the children (Broder *et al.*, 1999:549), low rates of uptake of dental healthcare are often reported. In Kenya, for example, Masiga and Machoki (2012:221) report that 81% of children with HIV/AIDS had not utilized any form of oral

healthcare. This was in spite of the finding that dental caries experience among the children was associated with reduced quality of life (Masiga and Machoki, 2013:86). The reasons for the poor utilization of oral healthcare among the children in that study were unclear. It is often reported that structural and/or psychosocial factors such as lack of health insurance, transportation and limited language proficiency are barriers to access and utilization of oral healthcare among children in low-income populations, (Woolfolk *et al.*, 1985: 141; Kelly *et al.*, 2005:1345; Barker and Horton, 2008:22). To date, there is very little empirical research that has explored the effect of culture in the African context, among the other contexts of care, in determining the utilization of oral healthcare among children from special population groups. It is possible that in the backdrop of state-mandated policies and procedures, culture and societal factors work together to militate against timely consumption of oral healthcare in named populations.

The present study postulates that culture and other societal factors among female caregivers intersect synergistically to produce and/or sustain poor utilization of oral healthcare for children with HIV/AIDS. For those reasons, the study was designed to explore the individual and societal factors that determine the utilization of oral healthcare for children with HIV/AIDS among female caregivers at three hospitals in Nairobi City County. The study, therefore, sought answers to the following research questions:

1. What is the influence of the culture of female caregivers on the utilization of oral healthcare for children with HIV/AIDS?
2. What is the effect of socio-economic factors among female caregivers on the utilization of oral healthcare for children with HIV/AIDS?

3. How do structural factors affect the utilization of oral healthcare by caregivers of children with HIV/AIDS?

1.5 Objectives of the study

1.5.1 General objective

To explore the cultural and societal determinants of the utilization of oral healthcare for children with HIV/AIDS among female caregivers in Nairobi City County, Kenya

1.5.2 Specific objectives

1. To describe the influence of culture among female caregivers on the utilization of oral healthcare for children with HIV/AIDS.
2. To establish the effect of socio-economic factors among female caregivers on the utilization of oral healthcare for children with HIV/AIDS.
3. To determine the significance of structural factors in the utilization of oral healthcare by female caregivers of children with HIV/AIDS.

1.6 Assumptions of the study

1. The culture of female caregivers has an influence on the utilization of oral healthcare for children with HIV/AIDS.
2. Socio-economic factors among female caregivers have an effect on the utilization of oral healthcare for children with HIV/AIDS.
3. Structural factors are significant determinants of the utilization of oral healthcare by female caregivers of children with HIV/AIDS.

1.7 Justification of the study

This survey was timely in adding insights into existing literature and addressing the knowledge gaps on oral healthcare utilization in a named cohort. The concept of studying the behavioural complexity of healthcare utilization has evolved with the course of time and ultimately become a tool for understanding how people employ the health care systems in their respective socio-cultural, economic and demographic circumstances. Creation of this knowledge involves a social science discipline working together with the medical profession and, yet, this important area of social sciences in oral healthcare has not been adequately developed. So far, there are huge gaps in such kind of information in resource-constrained economies, and the study, therefore, firstly addresses these gaps.

Secondly, while most African societies, Kenya included, are considered to have strong cultural orientations there is paucity of information on cultural beliefs about oral health and illnesses, functions of the teeth, beliefs related to oral pain and the methods of relieving it, or distinct references to remedies for treating oral conditions within the African cultural context. The intent and timing to seek healthcare is likely to be associated with the cultural beliefs of a specific population group, yet this has rarely been reported. The findings of this study, therefore, adds to the limited literature on understanding how culture, beliefs and practices specifically relate to oral health and shape the utilization of oral healthcare among a selected Kenyan subpopulation of female caregivers of children with HIV/AIDS. The investigator is not aware of any African anthropological studies that have documented this information.

Healthcare-seeking behaviour has emerged as a tool for assessing perceived ill-health through the remedial measures taken to utilize healthcare. With advent of the new era, female caregivers have

come out of their domestic confinement and increasingly become an important factor in the public health agenda of healthcare-seeking for their children. Thirdly, therefore, the study sheds light on the female caregiver's perspectives of oral health and illnesses by reporting on issues associated with oral healthcare-seeking for their children. It is a widely held tenet that mothers in resource-constrained economies may not have sufficient knowledge and health literacy to be able to recognize danger signs regarding their children's health, and may not have adequate empowerment to access appropriate health services. This study reports on the constraining factors that hinder low-income female caregivers from seeking timely oral healthcare even when they perceive their children to have dental illnesses or suffer ill oral health.

Fourthly, the study provides accounts of the caregivers' own perceptions of the healthcare system that delivers healthcare services to them, thus informing on the significance of structural factors as determinants of the utilization of oral healthcare among the caregivers. The healthcare system responsiveness specifically refers to the environment and the manner in which people are treated when they seek healthcare services. It has been argued that the utilization of healthcare is a function of both need-related as well as supply-induced factors that are strongly related to the healthcare system. Patient satisfaction with non-medical aspects of care represents a complex mixture of perceived needs, expectations and experience of care which is often associated with better compliance in utilizing healthcare. The study provides this information on caregivers' perceptions of quality of care and responsiveness of the health system particularly in the selection of health providers for oral healthcare.

Lastly, from a public health perspective, information garnered from this research may be utilized in designing interventional programmes that have positive impact in increasing the utilization of

preventive oral health services for children with HIV/AIDS. Health promotion addresses the things in the community that influence health and well-being in the context of their everyday lives, therefore, strategies that concentrate only on providing access to care may detract from the powerful effects of social stratification, power differentials, and the understanding of how cultures, beliefs and practices contribute to oral healthcare utilization. The findings of this study will be useful in teasing out the influence of culture from other potentially confounding factors such as income, education level and other societal determinants that are important predictors of the utilization of oral healthcare.

1.8 Scope and limitations of the study

This study collected data on the socio-demographic variables of female caregivers of children with HIV/AIDS attending the HIV-care clinics at GCH, MCRH and KNH in NCC, together with first-hand accounts of the female caregiver's oral health culture and practices and how they affect the utilization of oral healthcare of children with HIV/AIDS. Included also, were their perceptions of the oral health status of their children, and the constraints they face in utilizing oral healthcare. The respondents' annotations and experiences in utilizing oral healthcare were confirmed and given further shape and depth through holding key interviews with health workers at the hospitals' HIV-care clinics. The study was guided by the healthcare utilization model (Andersen and Newman, 1973), in order to gain in-depth understanding of the phenomenon under study.

The information garnered from the study was limited to the perspectives of *female* caregivers of children with HIV/AIDS. This decision to restrict participation to a cohort of female caregivers was informed by the findings of a previous study at KNH by the same author who observed that a relatively small number (11.8%) of male caregivers normally accompanied their children to the

HIV-care clinic (Masiga and Machoki, 2012:219). Due to this limitation, generalization of the results presented here should be done with caution.

Secondly, matters of health constitute confidential and sensitive information from patients. In particular, having HIV/AIDS attracts a certain degree of social stigma. In the process of data collection, sensitive information was sought from the respondents who, depending on their inclination, may give biased information. It was beyond the ability of the researcher to measure the respondent's state of mind and willingness to disclose personal information associated with HIV/AIDS. However, since privacy and confidentiality of the information was assured throughout the study, the respondents were encouraged to share as much relevant information as possible. The issue of recall bias was minimized by the inter-methods triangulation of data collection, which also facilitated validation of data through cross verification.

In other limitations, the study reveals little data about treatment carried out by alternative oral healthcare providers such as traditional healers. According to the study findings, very few respondents utilized these oral healthcare options, although a small number reported to have been to them before. Lastly, while the findings of this study may be used to suggest how best to approach interventional methods to improve the utilization of oral healthcare for children with HIV/AIDS within the framework of comprehensive healthcare, it was beyond the scope of the study to implement any interventional measures.

1.9 Definition of key terms

Caregivers are the biological and/or foster mothers, female relatives or female legal custodians, who provide unpaid primary care to the respective dependent children with HIV/AIDS. They are

concerned with the basic activities of the child's daily living, along with the concern, worry and emotional involvement that is entailed.

Cultural practices are the shared patterns of actions or oral health beliefs among the female caregivers of children with HIV/AIDS which defines their behavioural norms in the utilization of oral healthcare for their children.

Healthcare workers are the health professionals, including doctors, nurses, clinical psychologists and social workers who provide healthcare and psychosocial support to the caregivers and children attending the HIV-care clinics where the study was conducted.

Health provider is the person or place where the caregivers of children with HIV/AIDS visited when someone in the family required oral healthcare services. For this study, the oral health provider is distinguished from a 'usual source of care' which represents regular continual oral healthcare, including preventive oral healthcare.

HIV-care clinics are those specifically set aside for the care of adults and children with HIV/AIDS. Those utilized in this study are located within the hospitals that constituted the research sites, GCH, KNH and MCRH. The clinics utilize the services of different cadres of health personnel working together to provide comprehensive care for PLWHA.

Individual factors constituted the socio-demographics characteristics of caregivers of children with HIV/AIDS such as age, marital status, education level, occupation and household income, *as well as* caregiver's oral health beliefs and cultural practices, perceptions of disease severity, illness and wellness interpretations of oral diseases.

Oral health denotes the absence of oral diseases which range from dental cavities to oral cancer and/or other serious threats to oral health. It is considered a state of being free from mouth and facial pain and any disorders that limit the capacity to bite, chew, smile, speak and enjoy psychological well-being, and form the basis of caregivers' perspectives of their children's oral health status.

Oral healthcare, for purposes of this study, is medical care for children with HIV/AIDS that resulted in a state of being free from chronic mouth or facial pain, oral sores, periodontal (gum) disease, tooth decay, tooth loss or other diseases that affect the oral cavity.

Societal factors are the facts and experiences that influence caregiver's personal attributes and lifestyles. For the purposes of this study, these factors encompassed the predisposing, enabling and illness level factors that influence the utilization of oral healthcare.

Socio-economic factors are the life and socio-economic circumstances of the female caregivers of children with HIV/AIDS and the interface of these circumstances with oral healthcare utilization. They included characteristics such as caregiver's education level, income, resident locality, nature and diversity of occupational opportunities, societal norms and close social networks.

Structural factors are factors external to the control of the caregivers of children with HIV/AIDS that affect their utilization of oral healthcare services. These include their livelihood circumstances such as endemic poverty, health policies, and characteristics of the healthcare system which structures the provision of formal oral healthcare.

Usual source of care defined in this study is the particular oral health provider, clinic, health center or other place where caregivers of children with HIV/AIDS go for regular, continual oral healthcare, including preventive services, but not an emergency department. Having a usual source of care improves quality of care, enhances continuity and provides the connection with more specialized forms of care.

Utilization of oral healthcare refers to the ability of the caregivers of children with HIV/AIDS to source available oral healthcare provided at formal oral health providers with the purposes of attaining biomedical treatment for oral illnesses.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter is divided into two parts, namely, literature review and theoretical framework. The literature reviews key concepts relevant to the research problem under the following subheadings: Societal constraints on demand and preference for healthcare; determinants of the utilization of healthcare; and structural barriers in the utilization of healthcare, including oral healthcare. The second part is a discussion of the theory that guided the study, and the relevance of the health services utilization model to the study.

2.2 Societal constraints on demand and preferences for healthcare

Societal determinants of health are conditions in the social, physical and economic environment in which people are born, live, work and age; in other words, economic and social conditions that influence the health of people and their communities. These conditions are shaped by the amount of knowledge, money, power and resources that people have, all of which are influenced by policy changes. Increasingly, researchers have begun to examine influences beyond the individual to explain the concerns of access to healthcare thus, making a better understanding of social, economic, behavioural and attitudinal factors crucial in studies with the underpinnings of health promotion. According to O'Donnell (2007:2827), there are two sets of factors which may suppress demand for health care; those that limit ability to consume and those that lower willingness to consume, in the economist's parlance, constraints and preferences. Access to health care problems cannot be resolved without tackling each of these deficiencies. Constraints are determined by the income of the household, the charges made for health care and costs incurred to

reach health services, while the determinants of preferences for health care are identified as family and community influences such as culture and gender issues, health beliefs and practices, education and knowledge of the potential benefits of health care and quality of the services available. These factors are examined further in the following literature review, with regards to the utilization of oral healthcare.

2.3 Determinants of the utilization of healthcare

2.3.1 Familial culture and health beliefs

Culture is often defined as coherent, shared patterns of actions or beliefs specific to named groups of people. It provides basic roadmaps or social contexts that define behavioural norms and interpersonal relationships as well as unwritten rules for proper living. In health, culture organizes the group's norms of family life, including their recognition of illness and care-seeking practices around health or medical conditions. A low demand for healthcare and modern health interventions often derives from deep-rooted attitudes that reflect culture and social norms (Aday and Anderson, 1974:216). According to literature, culture is reflected in religion and religious practices, social norms, language, diet, family structure, health beliefs, preventive approaches and service utilization (Adair et al., 2004:109; Hilton et al., 2007: 435; Fisher-Owens, 2007:514). For example, in oral healthcare, it is suggested that satisfaction with care and trust in the dental system by parents reinforces the value of oral health (Milgram *et al.*, 1998:562; Graham et al., 2004:1556), whereas other factors such as perceived high costs of care (Kim and Telleen, 2004:1465; Schultz et al., 2001:324), fear of pain or general dental anxiety have negative influence on oral health care for children (Reisin et al., 1994:417; Reisine and Douglass 1998: 34; Tuutti and Lahti, 1987: 149). Specifically, culture has been reported to affect tooth-brushing

habits and methods, diet, perceived seriousness of tooth decay, and individual control over tooth decay among caregivers in both the United Kingdom and the United States of America, respectively (Adair *et al.*, 2004; Hilton *et al.*, 2007).

In healthcare utilization, cultural practices and health beliefs were also found to affect awareness and recognition of severity of illness and acceptability of service (Geissler *et al.*, 2000:1780; Stuyft *et al.*, 1996:168; Perez-Cuevas *et al.*, 1996:265). The continued preferences for traditional over modern therapies often leads to self-care, use of home remedies and consultation with traditional healers in rural communities in Southern Mali (Ellis *et al.*, 2007:705). Unfortunately, in some African countries, health-seeking cultural practices commonly result in delay in treatment-seeking for formal healthcare among women not only for their own health, but especially for their children's illnesses, such as reported in Kenya and Malawi (Nyamongo, 2002:384; Chibwana *et al.*, 2009:219; Abubakar *et al.*, 2013:5). In some cultural instances such as rural Guatemala, the advice of the older women in the house on matters of health is very instrumental and cannot be ignored (Delgado *et al.*, 1994:164). Some of the negative oral practices influenced by culture especially in poorer countries include pre-chewing of food for infants, sharing utensils during feeding, or sucking pacifiers to "clean" them. In carrying out these cultural practices, high cariogenic bacterial levels in saliva are transmitted to babies and infants (Li and Caufield, 1995:684; Sakai *et al.*, 2008:150). Further, in many societies in the East African region, socio-cultural oral practices include the removal of "plastic" canine tooth buds in infancy which is done in the belief that it prevents childhood illnesses (Acorsi *et al.*, 2003:25; Masiga and Musera, 2003:173; Mutahi *et al.*, 2010:96; Kahabukha *et al.*, 2015:2).

According to different cultural contexts, the norms of decision-making have a significant influence on the mothers' ability to seek treatment for their child's illness. For example, studies carried out in Nigeria and Kenya reported that decision-making is often the prerogative of males and senior household members, especially in making a decision about the seriousness of the illness, or the point at which to seek assistance beyond the home (Olubuloye *et al.*, 1991:205; Molyneux *et al.*, 2002:128). Similarly, in Pakistan, men being the decision-makers and in control of all resources, decide when and where women and children should access care (Rani and Bonu, 2003:180). It is, however, reported that adherence to cultural norms in health care-seeking may become influenced by the socioeconomic environment. Nxumalo *et al.* (2011:134) for instance, reported the fact that use of traditional therapies in South Africa declines with rise in income and education, suggesting that social norms are not inviolable, and the social is not completely divorced from the economic.

Epidemiological studies among different ethnic groups report that dental caries rates vary by ethnicity (Reisine and Litt, 1993: 417; Prendegast *et al.*, 1997:20; Shiboski *et al.*, 2003:45). Although race and ethnicity are considered markers for oral health status, being part of an ethnic group does not invariably lead a person to have poor oral health. It may be that underlying cultural beliefs and practices influence the condition of the teeth and mouth of these sub-populations, through diet, care-seeking behaviours, or use of home remedies. For example, reports on the oral health status of populations of the United States suggest that people from specific ethnic minorities often have poor oral health status (Watt and Sheiman, 1999:9; Petersen, 2005: 274; Shelly *et al.*, 2011:659). It is likely that certain cultural beliefs and practices common to the people in these minority groups influence their oral health status, for instance, values placed on having healthy primary teeth or expectations about preventive or therapeutic interventions.

According to Kiyak (1993:14), the various aspects of cultural ideas and practices may act as deterrents to optimal health outcomes. Uba (1992: 548), on the other hand, reports that framing the patient's illness in terms that are culturally understandable may make Western healthcare more acceptable.

2.3.2 Family socioeconomic status

A strong positive relationship exists between living standards and utilization of healthcare. There is evidence that the poor often benefit less from public spending on health (Makinen *et al.*, 2000:62), *albeit* they tend to be least healthy and most probably have the most to benefit from healthcare. In particular, the association of low socioeconomic status of the family and poor oral health in children is well reported in well-developed countries in Europe (Gibson and Williams, 1999:110; Kallestall and Wall, 2002:112; Petersen, 2005:276). Conversely, a higher socioeconomic status in the family promotes improved living conditions such as safe housing and ability to afford sufficient healthy foods. When considering the effects of socioeconomic disparity in oral health, children from higher social classes were reported to experience fewer caries, while those from lower classes had the poorest dental health (Crall *et al.*, 1989:428; Elley and Langford, 1993:136). According to Sundby and Petersen (2003:115), woeful living conditions and irregular oral health practices contribute to differences in the prevalence of dental caries among the poor in the Municipality of Copenhagen, Denmark.

One indirect facet of the effect of socioeconomic status is its influence on health literacy. The recognition of illness and knowledge of the potential benefits of treatment are prerequisites for healthcare demand (O'Donnell, 2007: 2826). Where a large proportion of the population is in poor health this becomes the norm and illness may not be easily recognized. Equally, if treatment

coverage is low there is less opportunity to learn of its benefit, the unfortunate outcome being continued toleration of illness and disease (O'Donnell, 2007:2826). A study carried out in Ghana specifically reported that several danger symptoms in children were not recognized by caregivers of children who became ill; some caregivers classified certain illnesses as 'not-for-hospital' and 'untreatable' by modern medicine' (Hill *et al.*, 2003:674). There is substantial evidence from developing countries such as Mexico, Egypt and Bangladesh to support symptom recognition linked to lack of awareness and ignorance as a barrier to utilizing health care for children (Tupasi *et al.*, 1980:85; Herman *et al.*, 1994:240; Perez-Cuevas *et al.*, 1996:268; Rashid *et al.*, 2001:254).

It is also stated that the socioeconomic environment can influence concepts of illness. Castro-Leal *et al.* (2000:68) postulated that reported illness is often higher among the better-offs than the poor. Additionally, Schellenberg *et al.* (2003:565) found that in Tanzania, differences in health knowledge reflected disparities in utilization where the better-offs were more likely than the poor to recognize signs of illness in a child who was less than five years and to seek care for a child when sick. In the United Kingdom, low socioeconomic status was associated with poor oral health knowledge and attitude of parents, which in turn, negatively affected their oral health practices and utilization of care (Williams *et al.*, 2002: 653). However, while lack of knowledge and health illiteracy can result in people not seeking care when they need it despite the absence of other barriers, it can also result in people seeking or receiving inappropriate care and paying for it. For example, studies carried out in Guinea Bissau and Zimbabwe reported that, while caregivers may seek medical care promptly for severely ill children, the choice of provider is often inappropriate, or the overall quality of care is poor and/or inappropriate (Sodeman *et al.* (1997:210; de Zoysa *et al.* 1998:210).

2.3.3 Family household income

The monetary costs of healthcare indicate that income is an important determinant of healthcare utilization and its dispersion. With out-of-pocket financing and limited access to credit being the norm in many poor countries, current household income is one of the binding constraints on the utilization of healthcare. In a market setting, a positive impact of income on consumption is expected where those with greater purchasing power may find that prices are less of a barrier to the utilization of healthcare. A low-income individual with competing interests, on the other hand, will choose to have additional consumption (of other goods) than additional healthcare (Ginson-Bautista, 1994:35). According to Mouradian *et al.* (2000:2629), children from low-income families are less likely to receive comprehensive dental care and more likely to have acute dental disease than children from middle-and upper-income families. Vanobberge *et al.* (2001: 260) also report that children in Finland whose fathers have a high occupational status and greater household income present with the lowest caries index values. According to Kelly *et al.* (2005: 1345), the expectation of poor oral health among low-income caregivers is among the factors for non-utilization of children's dental care.

It is the nature of financing in the developing world with heavy reliance on out-of-pocket payments that further strengthens the relationship between healthcare utilization and household income. O'Donnell (2007:2825) posits that risk-pooling and cross subsidization, possible with pre-payment systems, may break the dependency of healthcare utilization on current income. However, while considering demand factors that are amenable to policy intervention, it should be appreciated that household incomes may be amenable to control but they are assumed to be mainly affected by wider economic policies outside the specific control of the health sector.

2.3.4 Parental education and information

Parental education as a determinant of healthcare utilization is a complex variable. To some extent, education can improve the ability of individuals to produce health themselves through better lifestyles rather than relying on health services (Enscore and Cooper, 2004:71). In addition, better basic education can, through general improvements in literacy, influence the desire and actual use of health services. A frequently cited study in Pakistan, for example, found that maternal schooling was the most important factor influencing healthcare utilization and child survival (Agha, 2002:202). At the very least, education provides the consumer with the basis for evaluating whether they or a dependent requires treatment. Information on the best places to seek care is additionally required. Ahmed *et al.* (2005:113) report that this is one of the most significant determinants that predict the odds of an individual using self-care treatment from a drug store or treatment from a qualified allopathic practitioner.

According to Kinnby *et al.* (1995:109), who examined the influence of social factors in children with regard to dental experience and information, the educational level of caregivers is one of the important social background factors that directly influence children's dental health. In a couple of studies on the oral health of Finnish children, a higher prevalence of dental caries and lower tooth-brushing frequency was found among 3-year-old children living in rural areas with less education, compared with those from urban settings with higher education (Paunio *et al.*, 1993:6; Paunio, 1994:38). Several other studies among children of different nationalities have also reported the impact of parental/caregiver education on children's oral health status (Vargas, 1998; Nicolau, 2005:96; Szatco *et al.*, 2004:187)). In fact, the higher the parental education level, the more favourable is the oral self-care of their children. For instance, while it is well recognized

that oral health education and preventive measures help to reduce the need for tooth extraction, parents must be able to assimilate this information, understand the instructions provided and implement them as part of the child's daily oral health routine. Unfortunately, many parents may be only partially literate and, consequently, have difficulty in understanding the instructions on their child's caries prevention (Jackson, 2006:73). The fact that mothers of children in ethnic minority groups often receive only a few years of education results in poor communication skills and, consequently, poor dental health and service utilization (Sundby and Petersen, 2003:154). This argument is supported by Kelly *et al.* (2005:1347) who hypothesize that the strongest demographic factor associated with utilization of oral healthcare is caregiver education. In their study, they found that approximately three quarters of caregivers with non-utilization of dental care in the United States reported no more than a high school education, and more than half of utilizing caregivers reported at least some college education. They posit that better oral health beliefs and norms of caregiver responsibility for professional preventive care may explain the effects of higher parental educational attainment on service utilization.

2.4 Structural barriers in healthcare utilization

It is reasonable to postulate that individuals formulate personal opinions and behavioural intentions while negotiating their social environment against broader structural background factors. According to Roura *et al.* (2009:205) these 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 the healthcare system. For example, residents of rural communities may experience barriers to oral healthcare in the structural domain due to a high concentration of poverty, geographic isolation and 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.*, 2010:1). Structural factors are often 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 (Roura *et al.*, 2009:204). There are reports that consumers are sensitive to the way in which the time of utilization is spent, with high travel and treatment time causing reduced demand for services (Heller, 1982:277).

In oral healthcare, some structural barriers are provider-side issues such as too few dentists to meet regional demand, or too few dentists who will provide care to state-insured beneficiaries. Among children in America these were found to often limit the use of oral health services for low-income uninsured patients (Vargas *et al.*, 2003:155). In addition, having health insurance is widely recognized in several studies as critical in reducing financial barriers to dental care for children (Newacheck *et al.*, 2000:995; Lave *et al.*, 2002:238; Mofidi *et al.*, 2002:707; Siegal, 2004:527). It is postulated that, in itself, health insurance can have a mediating effect on other socioeconomic variables and access to care (Milgrom *et al.*, 1998:564; Lave *et al.*, 2002:238; Mofidi *et al.*, 2002:712). In the assessment of potential risk factors for development of caries in young children, lack of health insurance was strongly linked to a higher probability of having dental caries (Crall *et al.*, 1990:235). Still, the mere presence of insurance does not assure access to care, because the social health insurance may not be accepted by the majority of health providers. In the United States, for example, there are several reports that despite dental coverage by the state for all children qualifying for Children's Health Insurance Programme (CHIP), evidence strongly indicates that these populations are not receiving levels of dental care treatment

at par with privately insured patients (US Department of Health and Human Services, 2000). According to Bailit *et al.* (2006:807), the dental safety net, a network of public and voluntary sector organizations that provides dental services to low-income patients, lacks the capacity to meet the demands for dental care.

2.4.1 The role of prices of healthcare

Prices (charges for healthcare) play an important role in the utilization of healthcare. There is strong empirical support for the proposition that the poor are more price-sensitive than the better-offs (Litvack and Bodart, 1993:379; Castro-Leal *et al.*, 2000:71). As a result, increases in user charges will likely raise the share of healthcare consumed by the better-offs, unless effective mechanisms are implemented to shield the poor from these charges. Although the direct price of health services, the price of alternative health services and the relative prices of other health-enhancing inputs are mostly related to supply of services, financing healthcare through out-of-pocket payments makes prices an important barrier on the demand side for health services; in relative terms the payments for healthcare can be substantial on household budget. For the poorer populations where the cost of a hospital visit forms a significant percentage of per capita annual household income net of food expenditure, prices are expected to deter utilization. Accordingly, in the developing countries of South-east Asia, it is reported that the magnitude of household out-of-pocket expenditure on health is at times as high as 80 per cent of the total amount spent on healthcare per annum (Ha *et al.*, 2002:69). In Kenya, as well, it is postulated that oral healthcare financing from out-of-pocket user fees, compounded by lack of safety nets or health insurance to meet subsidy for costs of care has proved to be a fundamental barrier to essential oral healthcare among the population (National Oral Health Policy, 2012:2).

There is, however, other evidence that suggests that consumers, even those in low-income households, are willing to pay fees for better healthcare if the fees translated into improved access and reliability. The effect of price increases in deterring the use of healthcare may, therefore, be offset by quality improvements (Hotchkiss, 1988:227; Alderman and Levy, 1996:20). Also related to prices of care, are the informal payments for health services that also frequently exist, which are substantial in many public health systems. They may even be greater than the formal charges, or may exist when official charges do not. For example, in one region of India, the poor are said to pay almost as much to visit a “free” public health centre, as for a consultation with a private doctor (Banerjee *et al.*, 2004:8). In addition to the charges made by healthcare providers, travel costs and forgone earnings are other important costs of consuming healthcare in low-income settings. For example, in rural areas, the distances to healthcare facilities and the poor conditions of the roads mean time, effort, and cost required to arrive at the point of delivery can be substantial, with expected negative impact on healthcare utilization. Consumers of healthcare are sensitive to the way in which time of utilization is spent, with high travel and treatment time causing reduced demand for services (Heller, 1982: 277). Evidence exists that if increased user charges are combined with reductions in travel time and improvements in quality, utilization can increase, even for the poor (Castro-Leal *et al.*, 2000:72).

2.4.2 Healthcare system factors in utilization of healthcare

Healthcare system factors often shape individuals’ cost-benefit analysis of the utilization of healthcare. The poor quality of health services is a major problem in many developing countries (Wagstaff and Claeson, 2004:95; Hammer *et al.*, 2002:298). The findings of studies carried out in Northern India were that facilities opened and closed irregularly (Banerjee *et al.*, 2004:11), and the absenteeism rates of doctors and nurses was very high ((Banerjee *et al.*, 2004: 10; Chaudhury

and Hammer, 2003:29; Chaudhury *et al.*, 2006:95). Additionally, reports on poor people's experience of health and illness state that hospital staff can be hostile, even violent to patients (Dodd and Munck, 2001:26), and misdiagnosis was not uncommon (Wagstaff and Claeson, 2004:65). There are also reports on inappropriate prescribing and treatment of patients (Wagstaff and Claeson, 2004:78), and medicines being all too often unavailable, sometimes due to staff pilfering for use in private practice (Wagstaff and Claeson, 2004:121; McPake *et al.*, 1999:60).

These deficiencies in quality of care can have direct implications for access to effective health care; one expects that utilization will diminish in response to the poor quality of care offered. However, the low quality of public primary health care can result in patients forgoing ("bypassing") care at the nearest health facility and seeking care at a higher-level public facility or in the private sector (Filmer *et al.*, 2000:209). Linked surveys of healthcare utilization and facilities in rural Rajasthan (India) report very low usage of healthcare at public facilities. Despite the fact that there are no formal charges on user fees, the population mainly utilized private healthcare. This phenomenon occurred in response to the 'informal charges' levied for public care and the very low quality of care (Barnajee *et al.*, 2004:9). The survey also reports high staff absentee rates at the public facilities, and clinic closure during regular hours with no predictable patterns of hours of operation. Unfortunately, alternative care at private facilities may also be of dubious quality. The Rajasthan surveys found that almost two-fifths of 'doctors' operating in the private sector had no medical degree, others had no (para) medical training at all, or had not even graduated from high school (Barnajee *et al.*, 2004:13). There was also evidence of inappropriate treatment where a significant percentage of patients were given an injection on a visit to a private doctor compared to the public sector. It is, however, the convenience of the private sector- people know they will find the clinic open and staffed-rather than the effectiveness

of the care on offer that attracted patients away from the public sector. According to O'Donnell (2007:2827), the low utilization of poor quality public care is wasteful of resources and imposes cost on patients seeking care. Akin and Hutchinson (1999:146) further posit that providing health facilities near the people and charging little or nothing for care may be of small value unless the health system has or can raise the revenues necessary to provide sufficient quality service at the 'free' and 'convenient' facilities.

2.5 Theoretical perspectives on healthcare utilization

Health behavioural factors are influenced by health beliefs, attitudes, values, and knowledge that people have about their health, and subsequent perceptions of need and the use of health services (Hjortberg, 2003:755). From literature, it is clear that the utilization of healthcare is a multifaceted phenomenon in which the use of health services relates to several factors which include culture, health beliefs and values, social structure, as well as cost and quality of services. Consequently, families who strongly believe in the efficacy of biomedical medical or dental healthcare might use more of the formal services than families with less faith in the results of these forms of healthcare. Social structure, on the other hand, determines the status of a person in the community, his ability to cope with presenting health problems and the commanding resources to deal with these problems. Social determinants interact with biological and personal determinants at a collective level to shape individual risk behaviours, environmental exposures, and access to resources that promote health. Through the process of social stratification, individuals are differentiated based on attributes that are considered important in society, such as income, education, race and sex, which subsequently determines the provision of rewards. According to Patrick *et al.* (2006:3), stratification functions as a process that formalizes inequality in the form of unequal access to

valuable resources such as quality housing, education, healthcare and dental care. While the utilization of health services is viewed as a type of individual behaviour, it is, in effect a function of characteristics of the individual himself, characteristics of the environment in which he lives and some interaction of these individual and societal forces (Moore, 1969). Societal factors are important determinants of an individual's utilization of oral healthcare, which can be explained by models that view health services utilization taking into account both the individual and societal determinants and their synergistic interaction.

2.5.1 Theoretical framework

This study was guided by the classic model of health services utilization (Andersen and Newman, 1973) discussed below, the goal being, to develop an explanatory model of the determinants of oral healthcare services utilization for children with HIV/AIDS by their female caregivers.

2.5.2 The health service utilization model

This health services utilization model is a socio-behavioural model developed by Andersen and Newman (1973:112). The purpose of this framework is to discover conditions that either facilitate or impede health services utilization in a given population. The model originally focused on the family as the unit of analysis because the medical care an individual receives was considered most certainly as a function of the demographic social and economic characteristics of the family as a unit. Subsequently, there was a shift to the individual as the unit of analysis because of the difficulty of developing measures at the family level that take into account the potential heterogeneity of family members, for example, a summary measure of "family health status."

It was deemed more efficient to attach important family characteristics to the individual as the unit of analysis.

According to this model, an individual's access to and use of health services is considered to be a function of three characteristics; the first one is based on the individual's inclination to use available health services (predisposing), the second is related to their ability to access services (enabling), and the third is based on their illness level, as shown in Figure 2.1 below.



Figure 2.1: The health service utilization model

(Andersen and Newman, 1973, cited in Hausmann-Muela et al., 2003:12)

1) Predisposing factors: These are the socio-cultural characteristics of the individuals that exist prior to their illness, such as:

Social structure: Education, occupation, ethnicity, culture, social networks and interactions.

Health beliefs: Attitudes, values, and knowledge people have concerning healthcare and the healthcare system.

Demographic: Age and gender.

Possible additions: Genetic factors and psychological characteristics.

Predisposing factors are likely to influence an individual's health-seeking behaviour (Andersen and Newman, 1973, cited in Hausmann-Muela *et al.*, 2003:12).

2) Enabling factors: These are the logistic aspects of obtaining care, the means and know-how to access health services, for example:

Personal/Family: Income, health insurance, travel, extent and quality of social relationships.

Community: Available health personnel, available facilities and waiting time.

Enabling factors alone or in combination can determine utilization of available health services (Andersen and Newman, 1973, cited in Hausmann-Muela *et al.*, 2003:12).

3) Need factors: These are the most immediate cause of health service use, from functional and health problems that generate the need for healthcare services.

Perceived needs: This is how people view their own general health and functional state, as well as how they experience symptoms of illness, pain, worries about their health and whether or not they judge their problems to be of sufficient importance and magnitude to seek professional help.

Evaluated needs: Represents professional judgment about people's health status and their need for medical care. Need is anchored in perceptions of severity, total number of sick days for a reported illness, total number of days in bed, days missed from work or school, or help from outside (Hausmann-Muela *et al.*, 2003:12).

Each component of the model is conceived of as making an independent contribution to predicting, or explaining the use of health services. The model suggests a causal ordering where the predisposing factors might be exogenous (especially the demographic and social structure), some enabling resources are necessary but not sufficient conditions for use, therefore, some need must be defined for use to actually take place (Andersen, 1968). It is further hypothesized that the predisposing, enabling and need factors have differential abilities to explain use, depending on what type of service was examined. Hospital services received in response to more serious

problems and conditions would be primarily explained by need and demographic characteristics, while other services, like dental services considered as more discretionary would more likely be explained by social structure, beliefs and enabling factors (Andersen, 1995:4).

2.5.3 Relevance of the model to the study

The most recent description of the health services utilization model emphasizes the dynamic and recursive nature of health services use, while including the health status outcomes. It is postulated that, an individual will likely utilize oral health services if they believe that the treatment they received was useful to them. For this study, the health services utilization model is relevant in portraying the dynamic interplay of multiple contextual factors among the female caregivers, with input from the external environment and the healthcare system itself, which stimulates the intention to utilize formal oral health services for children with HIV/AIDS. The model includes feedback loops showing that outcomes derived from the use of health services can, in turn, affect subsequent predisposing factors and perceived needs for services as well as health behaviour in seeking oral healthcare. The model provided the conceptual framework for this research (Figure 2.2).

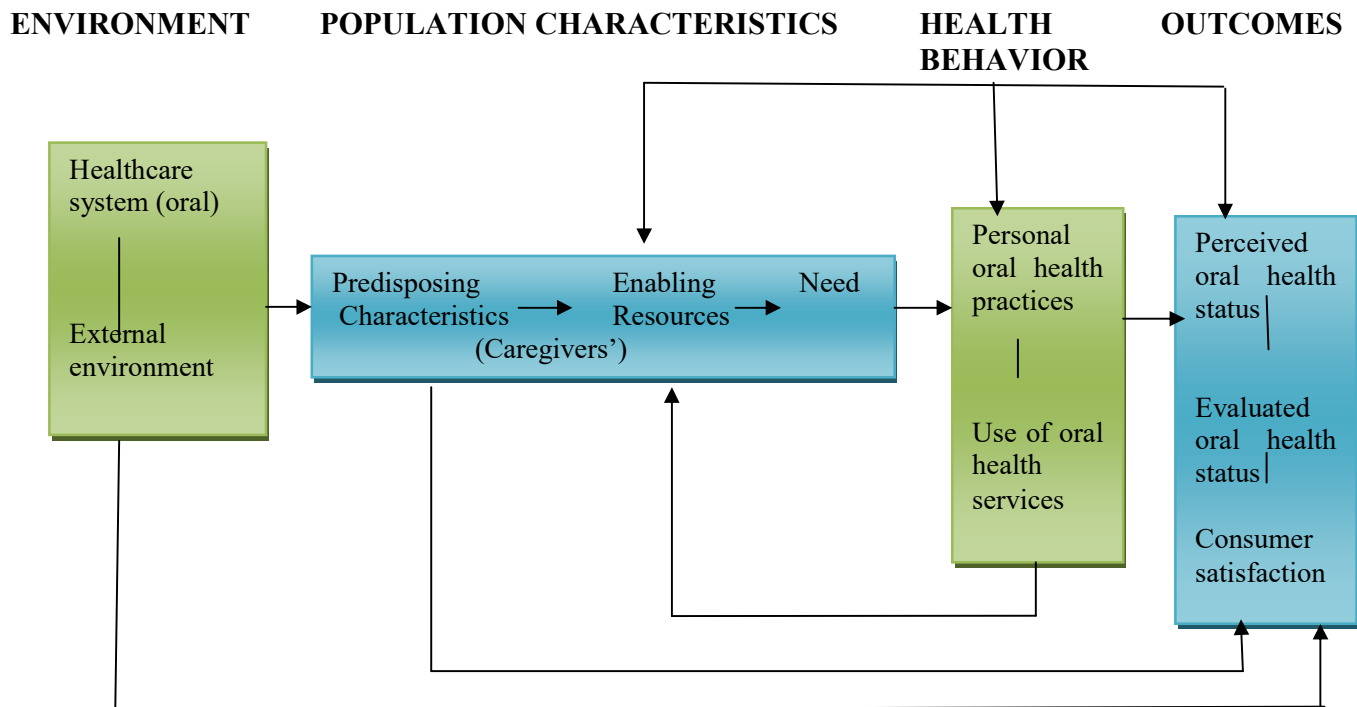


Figure 2.2: Conceptual Model (Source: Adapted from Andersen, 1995:8)

2.5.4 The study variables

The **independent variables** that operationalized the study were broadly categorized into the four sub-groups which constitute components of the health services utilization model. They were defined in the following manner:

Predisposing factors were those that rendered oral health services favourable, inclined and susceptible. Variables that fell under this group were child's age and sex, caregiver's age, education level, occupation, oral health culture, attitudes and practices.

Enabling factors denoted variables that engendered the use of oral health services by the caregivers. These included caregiver's household income, proximity of oral healthcare facility,

user-cost for oral healthcare services including opportunity costs, health insurance status, and third party influences such as social networks and religious influence.

Healthcare systems factors were variables that had to do with consumer satisfaction, and how caregivers perceived the non-medical qualities of care at the oral health facilities. The variables considered were type of oral healthcare facility visited (private or public), cleanliness and maintenance of the facility, availability of drugs, waiting time and attitude of health workers at the facility.

Need factors were those that are imperative and required action to be taken. The variables in the group included caregiver's knowledge of oral disease, caregiver's perception of child's oral health status, symptoms of pain and impact on child's oral health quality of life.

The **dependent variable** which is the utilization of oral healthcare was measured by the proportionate utilization of oral healthcare by children with HIV/AIDS, timeliness in utilizing needed oral healthcare and the factors that constrained the utilization of needed oral healthcare by caregivers.

CHAPTER THREE

METHODOLOGY

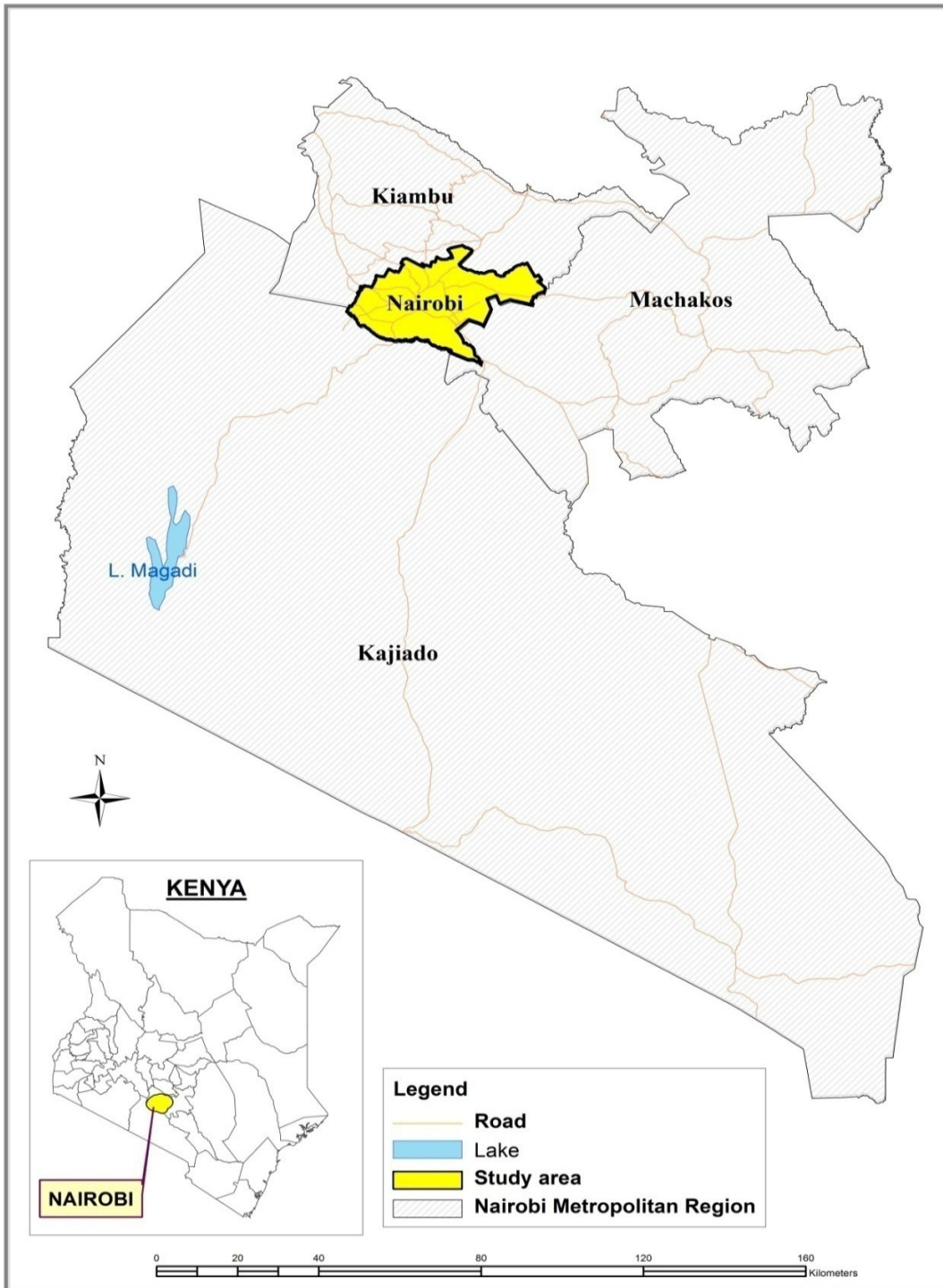
3.1 Introduction

This chapter describes the methodology that was used in the study. It starts by giving a description of the research area, its physical location and geographical features, healthcare infrastructure and economic activities, followed by information on the field sites where data collection was carried out. It goes on to describe the study design, study population and unit of analysis, sample size and sampling procedure, data collection methods, and data processing and analysis. Finally, it discusses the ethical issues that were taken into consideration and the measures put in place to fulfill the ethical requirements of the study.

3.2 Research area

3.2.1 Location and population

The study was carried out in Nairobi City County (NCC) which is located within the Greater Nairobi Metropolitan Region (GNMR). GNMR is made up of 4 out of the 47 counties in Kenya, namely, Nairobi City, Kiambu, Machakos, and Kajiado Counties. NCC covers an area of approximately 695.1 km², and has eight sub-counties, namely, Makadara, Kamukunji, Starehe, Lang'ata, Dagoretti, Westlands, Embakasi and Kasarani. The estimated number of people living in NCC in 2009 was 3,138,396, making it the most populous county in the country (www.nairobi.go.ke). Figure 3.1 presents a map showing the location of NCC within the GNMR.



Map drawn by Ms Regina Ng'ang'a, GIC Section, UoN).

Fig 3.1: Map showing the location of NCC within the GNMR

3.2.2 Health facilities

There are 496 registered health facilities within NCC as follows: County hospitals (3), Referral hospitals (2), Health centres (71), Dispensaries (156), Medical clinics (144), Maternity homes (14), Health projects (4), Nursing homes (21), VCT centres (39) and others (42). The doctor to population ratio is 1:23,000 (www.nairobi.go.ke).

3.2.3 Educational facilities

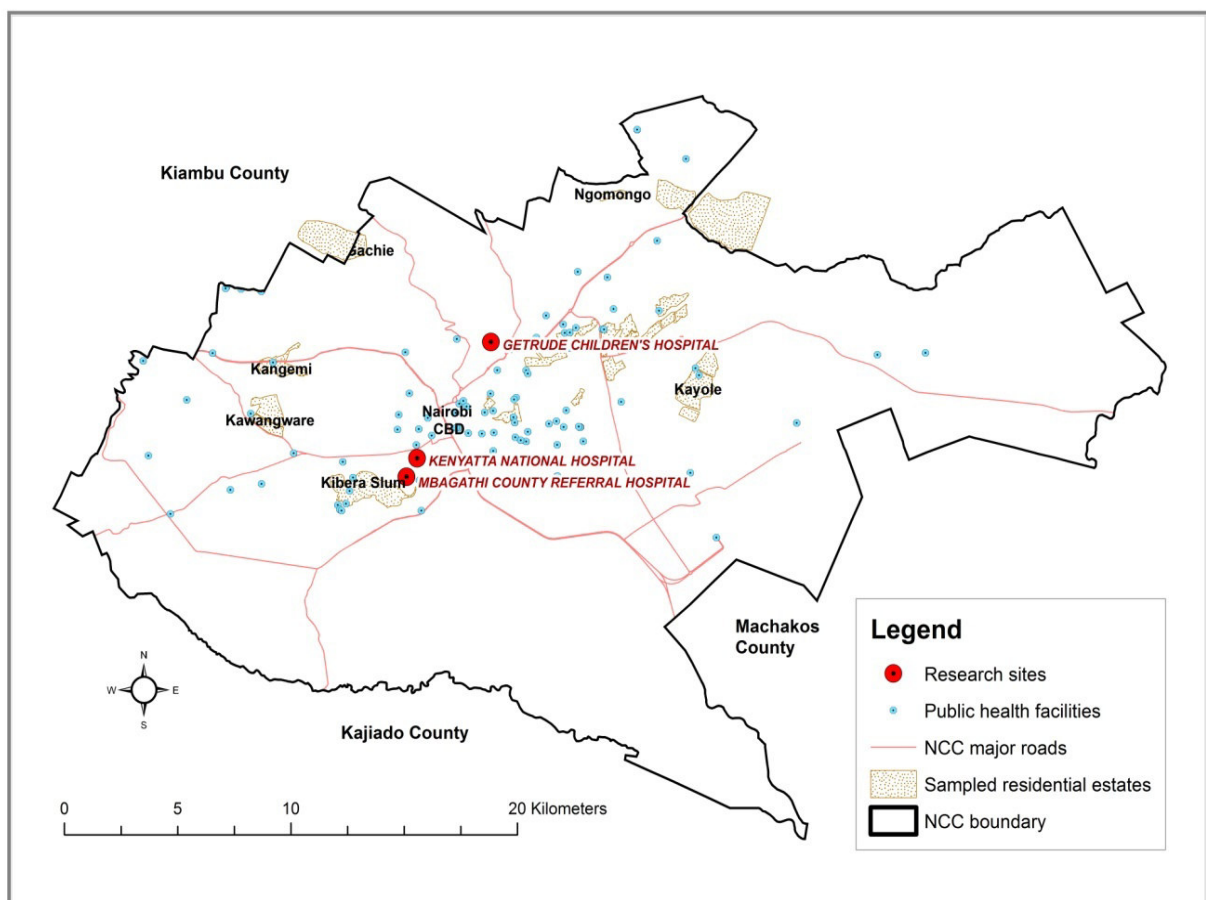
The educational facilities in the County include 1,241 primary schools, 335 secondary schools and over sixty public and tertiary institutions such as, universities, middle-level colleges and youth polytechnics (www.nairobi.go.ke).

3.2.4 Economic activities

The main economic activity in NCC consists of the industrial production of various goods on small, medium and large scale, trading, tourism, professional business services and commercial enterprises. Goods manufactured in Nairobi include clothing, building materials, processed foods, beverages and cigarettes. There is also a thriving “jua kali” sector that provides informal employment to carpenters, metal workers, vehicle mechanics and retailers. The areas around the NCC are prime agricultural lands, the principal crops being maize, sorghum, cassava, beans and fruits. Cash crops such as coffee are grown by small-scale farmers, who also engage in livestock and poultry keeping. Horticulture is a new agricultural growth sector, for example, flower exports are an important source of foreign exchange (www.nairobi.go.ke).

3.3 Research sites

The study was conducted at three hospitals which boast the largest HIV-care facilities in NCC namely, Getrude Children’s Hospital (GCH), Kenyatta National Hospital (KNH) and Mbagathi County Referral Hospital (MCRH). A map showing the location of the hospitals is presented in Figure 3.2, including the public health facilities in NCC and sampled residential estates.



(Map drawn by Ms Regina Ng'ang'a, GIC Section, UoN).

Figure 3.2: Map of NCC showing location of the research sites GCH, KNH, and MCRH. Public health facilities and sampled residential estates in NCC are also presented.

3.3.1 Gertrude Children's Hospital

Gertrude Children's Hospital (GCH) is located in the Muthaiga area of NCC. According to historical data, GCH was founded in 1947 with donation of land by Colonel Ewan Grogan in memory of his beloved wife Gertrude Edith. GCH is the largest and most well-known children's hospital in Kenya and the region, having been in service for over sixty years. It is registered as a non-profit organization. GCH has a strategic geographic location that makes it accessible to the affluent population who reside in the area within which it is situated, as well as serving the low-income population from the surrounding informal settlements such as the Githogoro and Gachie slums. The Sunshine Smiles Clinic (SSC) is the affiliated HIV-clinic, which attends to the medical care needs of children with HIV/AIDS. According to hospital records, GCH has a current enrollment of approximately 600 children out of whom about 440 children are active-in-care. Healthcare services for children with HIV/AIDS at GCH were started in 2002, with only a few clients who could afford treatment. However, through partnership with APHIA II-NAIROBI (USAID) initially, and currently through AFYA KIJIKI and GETRUDE FOUNDATION, the clinic offers quality comprehensive HIV-care services *free of charge* to both adults and children who, would otherwise, not be able to access treatment for HIV/AIDS. Information on patients' profiles at SSC reveals that more than 60% of the patients come from the surrounding informal settlements, they are of low-income status and live on less than 1US dollar a day. Most of the families are from female-headed households and 52% of the children are orphans (www.gerties.org). The hospital has made some pro-poor efforts which include provision of transport through a courtesy bus and ensuring that most patients have the National Hospital Insurance Fund (NHIF) cover that can serve in the outpatient set up.

3.3.2 Kenyatta National Hospital

Kenyatta National Hospital (KNH) is the oldest hospital in Kenya. Founded in 1901 with a bed capacity of 40, it served as the Native Civil Hospital at its inception, renamed King George VIII Hospital in 1952, and later renamed Kenyatta National Hospital (KNH) after Jomo Kenyatta the founding father of the Nation, following Kenya's independence from the British Government. Currently KNH has a bed capacity of 1,800, and a headcount of over 6,000 staff members. The University of Nairobi (UoN) Medical School and the government Medical Training College (MTC) are located within the premises of KNH. The hospital, operating under the auspices of the National government, plays a major role in healthcare delivery in the country and the African region, receiving referral cases for specialized healthcare from local institutions within and outside the country. In 2013, patients with HIV/AIDS occupied about one-third of the hospital beds. While some of these were already on treatment, it was still relatively common for patients with advanced AIDS to arrive at the hospital having never been tested for HIV-infection (Moyer, 2014:151). Towards the back of the sprawling complex of buildings that make up the hospital, one finds the HIV-care clinic which is housed physically and administratively by the hospital. KNH currently houses the largest HIV-clinic for comprehensive care of both adults and children with HIV/AIDS, with approximately 1,000 children enrolled, and more than 700 children active-in-care (Hospital records). KNH receives a great deal of financial support from various international funding agencies, notably, since 2010, the Partnership for Advanced Care and Treatment (PACT). PACT is the lead partner on a 5-year CDC/PEPFAR grant to develop centres of excellence in some of Kenya's top public hospitals. Antiretroviral therapy (ARV) and other supportive treatment is offered *free of charge* to all PLWHA who attend.

3.3.3 Mbagathi County Referral Hospital

Mbagathi County Referral Hospital (MCRH) is a public hospital located in Kenyatta Golf Course Estate, off Mbagathi road, Dagoretti sub-county of NCC. It was built in the 1950s to offer healthcare services mainly for infectious diseases that required isolation, such as tuberculosis, measles, meningitis and leprosy. Thus, historically, the hospital was known as the ‘Infectious Diseases Hospital (IDH). MCRH initially operated under the King George VI Hospital (currently KNH), however, in 1995 IDH was transformed into an autonomous hospital, though with poor and dilapidated facilities. MCRH is one of Nairobi’s busiest hospitals, being located adjacent to one of Africa’s largest informal settlements. The hospital operates under direct governance of the NCC, with a patchwork of funding from a variety of donor governments including the United States (US). It provides a broad range of in-and-out patient services for the surrounding population which goes a long way to decongest services at the KNH. As the hospital is located at the edge of Kibera, an area of the city that is often referred to in developmental literature as “the biggest slum in Africa”, a great many, though certainly not all of its patients, are likely to be poor and working class. According to hospital records, approximately 700 patients attend the MCRH daily with 50-70% of these having been diagnosed with HIV/AIDS. The HIV-clinic receives referrals from every department of the hospital and beyond. According to the hospital records, many of the children seen at the HIV clinic are orphans, of whom approximately 438 are active in care for HIV. HIV related services and drugs are offered *free*, however, chest x-rays and medications beyond the core TB and HIV drugs are ordered on prescription.

The selection of field sites for the study was purposive, and was based on the inherent characteristics and geographical locations of the three hospitals. GCH was selected for its

exclusivity in being the only children's hospital in the country, and its location north of the city in Gigiri, one of the up-market suburbs in the NCC, *albeit* serving the poorer population in the surrounding informal settlements as well. Despite bearing the tag of 'a private' hospital, HIV-care services at GCH are donor-funded and offered free of charge to all PLWHA. On the other hand, KNH, the nation's largest referral hospital was selected owing to its magnitude in size and patient numbers. The hospital offers a wide range of services which attract a diverse patient population from other sub-hospitals within and without the NCC. MCRH is second in size only to KNH, and serves as the NCC referral hospital. It has a unique location in the vicinity of Kibera, the largest informal settlement in Nairobi.

3.4 Research design

This was a cross-sectional and descriptive hospital-based survey in which both quantitative and qualitative methods of data collection were employed. The use of mixed methods was adopted to improve exploration of the phenomenon under study from different perspectives to facilitate validation of data through cross-verification. In order to address the study objectives expansively and ensure systematic collection of data the field work was structured into three phases, the first of which consisted of a trial run aimed at pre-testing the survey questionnaire to refine it and ensure that the interviews at the time of the survey would be carried out with ease and responses from the respondents would be maximized. The pre-testing of the survey instrument was carried out among female caregivers attending the dental hospital at the School of Dental Sciences (SDS). This phase also formed the preparatory stage for the fieldwork in which several meetings were held with institutional heads at the selected hospitals, so as to sensitize them and seek permission

to carry out the study. The process accorded the researcher an opportunity to cultivate the necessary rapport to facilitate the operations of the study.

In the second phase, a quantitative survey was conducted among female caregivers attending the HIV-care clinics at the three hospitals, using the pre-tested survey instrument. This was carried out in face-to-face interviews with the PI, the purpose of which was to collect socio-demographic data and other quantitative data relevant to the research objectives, such as the caregivers' individual health beliefs, attitudes and cultural practices in oral health, and their experiences in the utilization of oral healthcare for children. In the third and final phase, qualitative data were collected, specifically through focus group discussions (FGDs) with the caregivers, as well as key informant interviews (KIIs) with selected healthcare providers at the HIV-care facilities, comprising of doctors, clinical officers, nurses, psychologists and social workers. These were selected for their professional expertise and perceived likelihood to provide insights relevant to the study objectives. These informants were deemed to have useful insights related to the study objectives through their personal interactions with the caregivers. Additionally, case narratives were conducted among caregivers closely identified with the phenomenon under study. Secondary data collection and direct observation of hospital activity was on-going throughout the period of study as supplementary methods of data collection.

3.5 Study population and unit of analysis

The study population comprised female caregivers attending the three selected hospitals, specifically those that accompanied their children to the HIV-clinics. The unit of analysis was the individual caregiver. The inclusion criteria were (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 clinics.

3.6 Sample size determination

The sample size for the survey was calculated using the statistical formula recommended for cross-sectional studies by Fisher *et al.* (1998).

$$N = \frac{Z^2 P (1-P)}{d^2}$$

Where:

N= the desired sample size

Z= the standard normal deviate usually set at 1.96 which corresponds to 95% confidence level

P = 19%, the reported prevalence of utilization of oral healthcare among children with HIV-infection (Masiga & Machoki, 2012)

d= degree of accuracy desired, set at 0.05

Therefore:

$$N = \frac{1.96^2 \times 0.19 \times 0.81}{(0.05)^2}$$

N= 236

Thus, the calculated study sample size was 236 female caregivers.

Proportionate stratification was further utilized to assign the sample size for each stratum or hospital category, according to the population of children enrolled and active-in-care at each of the facilities.

3.7 Data collection methods

3.7.1 Secondary sources

Secondary sources were used to get basic information on the research problem. These included published and unpublished articles and reports, journals, essays, theses and dissertations, and electronic and print media sources, including the internet. The information formed the basis for literature review and identification of the gaps in knowledge, formulation of the research questions and objectives as well as the theory that was used to guide the study. Collection of this kind of data was a continuous exercise throughout the study.

3.7.2 The survey method

A standardized questionnaire consisting of open-ended and closed-ended questions was used to collect data on oral health perceptions, beliefs, and cultural practices among the respondents, as well as their experiences in the utilization of oral healthcare (Appendix 2). To get individual respondents for the survey, *purposive* sampling was carried out of female caregivers attending the HIV-care clinics at the three hospitals, using the inclusion criteria. The caregivers who were accessible and met the inclusion criteria were recruited *conveniently* on a daily basis until the required sample size at each hospital was attained. The survey was conducted by the researcher in face-to-face interviews with the selected caregivers.

3.7.3 Focus group discussions

The purpose of the focus group discussions was to grant the study an opportunity to revisit emerging issues from the survey, without necessarily going back to the same respondents. The researcher enlisted the assistance of the nurse in charge at each HIV-care clinic, to *randomly*

select the discussants in line with the inclusion criteria. A total of six FGDs were undertaken upon completion of the survey, two at each of the hospitals. The FGDs were conducted by the PI who was the moderator, and a research assistant who was the recorder and note-taker. The discussions centered on caregivers' cultural beliefs and practices, perceptions of their child's oral health status and their experiences in utilizing formal oral healthcare services for their children (Appendix 3).

3.7.4 Key informant interviews

These interviews involved collecting data from nine key informants (KIs) who are health workers at the HIV-care facilities. The aim was to capture the health worker's personal insights into the caregivers' behaviours in utilizing healthcare, in particular, how societal contexts shape and constrain the caregivers' ability to utilize oral healthcare. Key informants for the interviews were *purposively* selected for their professional expertise and perceived likelihood to provide rich and comprehensive information on the phenomenon under study. They comprised two doctors, one clinical officer, two counsellors, two nurses, and two social workers. The KIIs, three at each hospital, involved face-to-face conversations carried out by the PI, using a key informant guide (Appendix 4).

3.7.5 Case narratives

Narratives on accounts of lived experiences were generated from six caregivers of children with HIV/AIDS. The respondents for the CNs were identified during the survey, and *purposively* selected for reasons of having been infected and/or affected by dental pain and/or oral disease. The objective was to gain first-hand their story and, in particular, their coping mechanisms while seeking oral healthcare and utilizing formal oral health services for their children within the

context of their socio-ecological environment. Since matters of health affect individuals in different ways, the personal accounts helped to develop further understanding of the caregivers' experiences in line with the objectives of the study. The narratives yielded rich qualitative data on the adversities of living with HIV/AIDS, the pain and suffering caused by oral manifestations associated with the condition, lack of oral health awareness and the difficulties in healthcare-seeking for advanced oral diseases. The narratives were conducted using a case narrative guide (Appendix 5).

3.7.6 Direct observation

Direct observation was applied throughout the fieldwork to complement the other qualitative data collection methods. It has unique advantages in that it allows the researcher to gain general insights, including the range of activities taking place in the field sites without the study subjects knowing that they were being studied, thus capturing the natural environment at the HIV-care facilities. In the process of direct observation, the researcher was able to confirm and corroborate information obtained from the other methods of data collection. Direct observation was guided by use of an observations checklist (Appendix 6).

3.8 Data processing and analysis

Quantitative data from the survey were coded and entered into a micro-computer using MS Access, and analyzed using the Statistical Package for the Social Sciences (SPSS) programme Version 19.0. Where it was deemed necessary, cross-tabulation of variables was undertaken and tests of significance presented. Qualitative data were labelled and keyed-in using codes assigned to open-ended questions. The data were entered into a computer using ATLAS *ti* 8 for Windows

computer software, to assist in the categorization and matching process, content analysis and annotation of the important features and findings of study. The researcher was responsible for organizing the findings into common concepts and themes according to the study objectives and responses that were obtained from the study participants in order to obtain replicable and valid inferences on the caregivers' utilization of oral healthcare for children with HIV/AIDS. The case narratives aptly described as 'voices of the caregivers', were reported verbatim without any attempt to alter or interpret the meanings.

3.9 Ethical considerations

Ethical clearance to carry out this study was obtained from the Kenyatta National Hospital-University of Nairobi Ethical Review Committee (KNH-UON E.R.C- P631/10/2014), whilst permission to carry out the study was sought from the administration of KNH, GCH and MCRH. Informed consent (Appendix 1), was sought from the caregivers after full explanation of the research objectives and activities in a language that was clearly understood by the respondents. Participation in the study was purely voluntary and this was made clear to the respondents before commencement of the study. Privacy for all respondents was ensured during interviewing and consent was sought to tape-record the interviews. The names of individual respondents did not appear on the questionnaires and subsequent reports and publications emanating from this study will not bear any names. All data were kept confidential from collection to storage, according to the UoN research ethics. There were no monetary gains for respondents in this study; however, oral health education and information was given to all participants and children reported to have dental caries and oral pain were referred to the University of Nairobi-School of Dental Sciences (UON-SDS) where the researcher is domiciled, for further review and management.

CHAPTER FOUR

PERCEPTIONS, BELIEFS AND CULTURAL PRACTICES IN ORAL HEALTHCARE

4.1 Introduction

This chapter presents part findings of the study, mainly from the survey and in part from focus group discussions with the caregivers. It begins with a description of the socio-demographic characteristics of the respondents, and then moves on to present findings on the respondents' beliefs in, and perceptions of oral health, cultural practices in infant teething, and the use of traditional and self-care remedies. Also presented is the effect of HIV/AIDS stigma among respondents on the utilization of oral healthcare.

4.2 Distribution of respondents by hospital categories

A total of 221 caregivers were recruited into the study; 45 % were drawn from KNH, 28% from GCH, and 27 % were from MCRH (Table 4.1). The distribution of respondents across the hospital categories was done proportionately to correlate with the number of children enrolled and active-in-care at the respective hospitals.

Table 4.1: Distribution of respondents by hospital category

| Hospital category | Frequency | Percentage |
|--------------------------|------------------|-------------------|
| GCH | 61 | 28 |
| KNH | 100 | 45 |
| MCRH | 60 | 27 |
| TOTAL | 221 | 100 |

(Source: Survey data, 2016)

4.2.1 Hospital visits and observations

This study was initiated at the Sunshine Smiles Clinic (SSC), the HIV-care clinic at GCH, which also served as the first respondent contact. Tuesday of every week is the day set aside for the medical care of children with HIV/AIDS at this facility. At commencement of the study, respondent flow was considerably slow with approximately 5-7 caregivers attending on the busiest clinic days. This caused the researcher to spend a longer period of time at this facility than had been anticipated. However, the time was well spent in creating harmony with the staff at the clinic which resulted in a relaxed and pleasant environment to carry out the field work. In contrast, the prevailing atmosphere at KNH was quite different. There was a high flurry of activity and several caregivers attended with their children on any given day, aside from the three days allocated for the children's clinics; thus, the researcher was able to interview several caregivers on any single day. Although the rapport with staff at the clinic was not as close, nonetheless it was cordial and professional in facilitating my field work at the hospital. At MCRH, there was strict adherence to the clinic schedule, with Wednesdays only being the day set aside for the children's clinic, thus, respondent interviews were carried out only on the designated day. The clinic was observed to be fairly busy at any given visit.

It was further observed that HIV-care clinics at GCH and KNH had structured child-friendly areas denoted specifically for children to play in while awaiting treatment. Additionally, at KNH, a paper artist was in attendance to keep the children engaged in drawing, colouring and other paperwork activities. At the MCRH, there did not appear to be any effort to customize child-friendly activities. Notwithstanding, all the health facilities accorded the researcher a room and adequate space and privacy in which to carry out interviews with the respondents and the health

workers. Despite the sensitive nature of the study subject matter, the respondents, once they understood the objectives of the study and the non-incriminating nature of the information that was being sought, readily assented to the study. Therefore, there were no major problems encountered during the field work at any of the hospitals.

4.2.2 Age and sex of children visiting HIV-clinics

The average age of the children visiting the HIV-clinics was 9.64 years (± 6.46 SD); however, the children at MCRH, were found to be significantly older than those at KNH or GCH ($p=0.00$). The male to female ratio was 1:1.2 without significant difference in sex distribution of the children at the three hospital categories ($p = 0.93$). The ages of the children with HIV/AIDS who attended the HIV-care clinics at the three hospitals during the period of the study are presented in

Figure 4.1

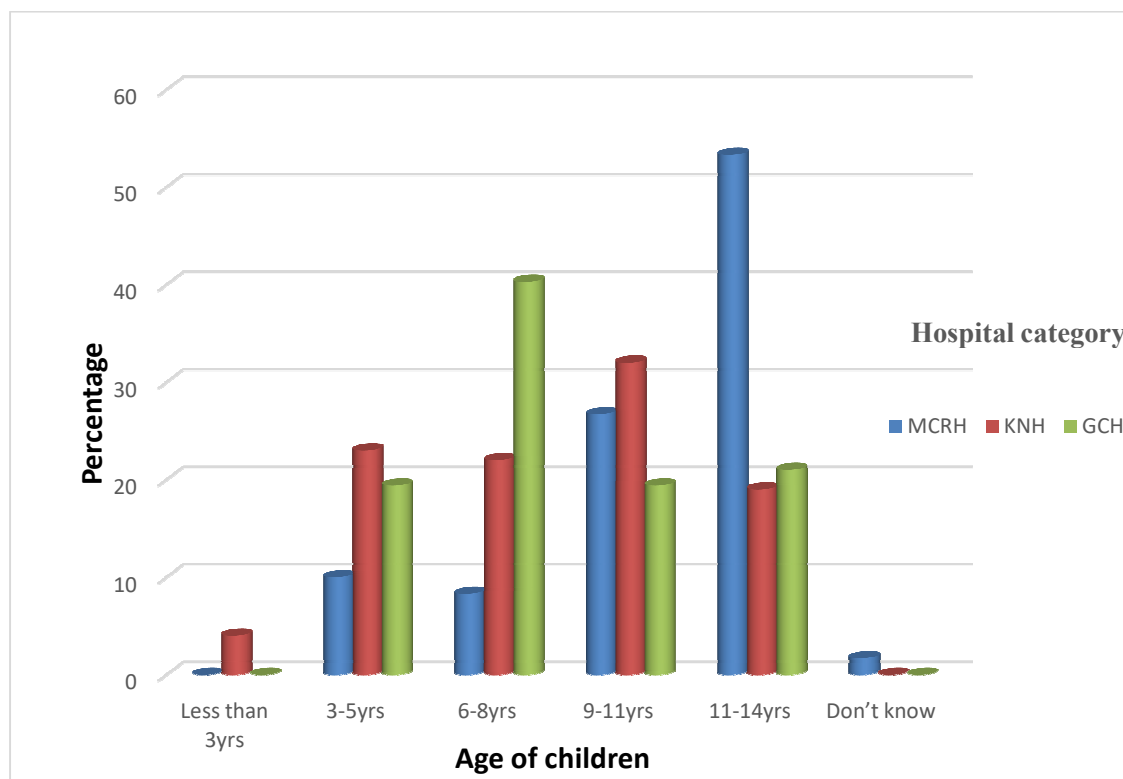


Figure 4.1: Age of children attending the HIV-care clinics (Source: Survey data, 2016)

4.3 Socio-demographic characteristics of the caregivers

4.3.1 Age

The loss of a biological mother is a likely event in this population cohort; therefore, the impact of demands on age in care-giving for children with chronic life-long condition may thrust adoptive caregivers into the role at very young or very old ages. The study findings on caregiver's age indicated that most caregivers were in the young to middle-aged categories. The highest percentage (41%) was in the age category of 34-41 years, followed by that of 26-33 years (27%). The category of caregivers aged 42-49 years was 17%, while at the extremes ends were caregiver age categories of above 50 years (11%), and 18 -25 years (4%).

4.3.2 Marital status and relationship with child

Marital status commonly affects parental decision-making in the utilization of formal healthcare services. The study findings indicate that more than half (59%), of the caregivers were in stable marriages, 14% were widowed, 12% were separated or divorced and 15% were single mothers. Given the psychological stigma that is frequently associated with HIV/AIDS and the phenomenon of discordance that may exist among couples, it was inspiring to note that respondents had relatively low rates of divorce or separation among them. If anything, the rate of spousal survival was found to be fairly high, which may imply improved accessibility to ARV medication among the study population which greatly reduced the morbidity and mortality rates of HIV-infection.

It is a common finding in most African societies that the care of a sick child is the domain of the mother. In this study, 76% of the respondents were biological mothers of the children they brought to the hospital; others, while not being biological mothers, were related to the child and

were mainly grandmothers (17%), and aunts (5%), while the remaining 2% of the respondents were unrelated to the child and were drawn from foster homes. The respondents had good recollection of their ages and had no qualms about disclosing the same, nor the status of their marriages. In fact, several times they were keen to elaborate on their lived experiences in marriage, and how they had acquired their HIV-positive status, and the researcher had to keep redirecting their responses to focus on the information that was required by the survey instrument. The ages and marital status of the respondent at the three hospital categories were not significantly different ($p= 0.522$ and $p=0.549$) respectively. Therefore, subsequent results are discussed collectively.

4.3.3 Educational status

It is generally postulated that better basic education can, through general improvements in literacy, increase the desire and actual use of health services. Education level was thus considered to be an important variable in this study. The highest percentage of respondents 43% had attained primary level education. This was followed by 33% of the respondents who had attained secondary level education. Those that had attained tertiary or college education, or other post-secondary school training were much fewer (18%), whilst 5% of the respondents did not attend school at all. The respondents rationalized that they came from poor family backgrounds and, therefore, the school fees required to pursue further education was beyond their parents' reach. The low-level of formal schooling was reflected in the caregivers' choice of language for communication during the focus group discussions, where only 2-3 participants in any one group were able to communicate in fluent English. They were, however, very confident in expressing themselves in Kiswahili, and this became the main language of communication in the discussions.

4.3.4 Main occupation

Parental occupation is often closely related to their education level and, frequently, gives an indication of the socioeconomic status of the family. By and large, it affects the family's household income and ability to afford formal health services. It was a little more difficult to elicit the main occupation of the respondents in the study as most of them had no clear explanation on what they did to earn a living. They mostly reported occupations that involved a little bit of this and that, depending on what the emergent need of the day was and what resources were available to keep them occupied. What was clear, however, was that nearly half of the respondents (49%) were in non-formal employment of sorts. Those that were in formal employment were 28%, where they mostly held low-level jobs such as cleaners, security guards and clerks in government offices and/or in private companies, although a small number of these had managerial and lecturer's position; 6% of caregivers were engaged in menial/casual labour at various locations, while 17% were unemployed and mostly stayed at home as housewives. Those respondents who were in informal employment mainly engaged in small-scale businesses such as market stalls and *kiosks* where they sold fruits and vegetables and other consumables, and they made homemade beadwork and curios. Another group of women were tailors, hairdressers and shopkeepers; while others were occupied with hawking of second-hand clothes, and peddling small goods and commodities.

4.3.5 Household income

The household earnings reported by the respondents seemingly placed them at the middle-lower to lower end of the national economic pyramid. About two-fifths of the respondents (41.9%) reported to live on less than, or equal to KES 10,000 monthly. The other respondents reported

incomes of KES 11,000- 20,000 (19.4%), KES 21,000- 30,000 (9.9%), and KES 31,000-40,000 (7.2%). Only 14.4 % of the respondents reported household incomes of KES 40,000 and above. Additionally, the respondents were observed to reside in high population-density neighbourhoods and the informal settlements of NCC, from where they travelled to the service locations of the HIV-clinics. When healthcare is needed but is delayed or not obtained as a result of lack of financial resources, people's health is likely to worsen. This in turn results in further loss of income and higher healthcare costs both of which contribute to increased poverty.

It was not always very clear among the respondents who were married, whether the household income they reported was solely the respondent's own earnings or if there were additional inputs from their spouses. However, it may be deduced from the nature of the occupations among the caregivers, that the women themselves were active income-earners and they contributed in a meaningful manner to the overall household income, which may imply that they are likely to have some control over household expenses. There was no significant difference in household income levels between the caregivers at the three hospital categories ($p > 0.05$), hence, subsequent data was analyzed collectively. The socio-demographic characteristics of the respondents are summarized in Table 4.2 below.

Table 4.2: Sociodemographic characteristics of respondents

| Variables | Category | Frequency | Percentage |
|-------------------------|---------------------|------------------|-------------------|
| Age (years) | 18-25 | 9 | 4 |
| | 26-33 | 60 | 27 |
| | 34-41 | 91 | 41 |
| | 42-49 | 38 | 17 |
| | >50 | 15 | 7 |
| | Don't know | 8 | 4 |
| Relationship with child | Biological mother | 168 | 76 |
| | Grandmother | 38 | 17 |
| | Aunt | 11 | 5 |
| | Unrelated | 4 | 2 |
| Marital status | Married | 130 | 59 |
| | Widowed | 31 | 14 |
| | Separated/divorced | 27 | 12 |
| | Single mother | 33 | 15 |
| Highest education level | No formal schooling | 12 | 5 |
| | Primary level | 95 | 43 |
| | Secondary level | 73 | 33 |
| | Tertiary level | 40 | 18 |
| | Don't know | 1 | 1 |
| Employment status | Informal | 108 | 49 |
| | Formal | 62 | 28 |
| | Casual (menial) | 13 | 6 |
| | Unemployed | 38 | 17 |
| Household income (KES) | = < 10,000 | 93 | 42 |
| | 11,000-20,000 | 42 | 19 |
| | 21,000-30,000 | 22 | 10 |
| | 31,000-40,000 | 15 | 7 |
| | 41,000-50,000 | 11 | 5 |
| | >51,000 | 20 | 9 |
| | Don't know | 18 | 8 |

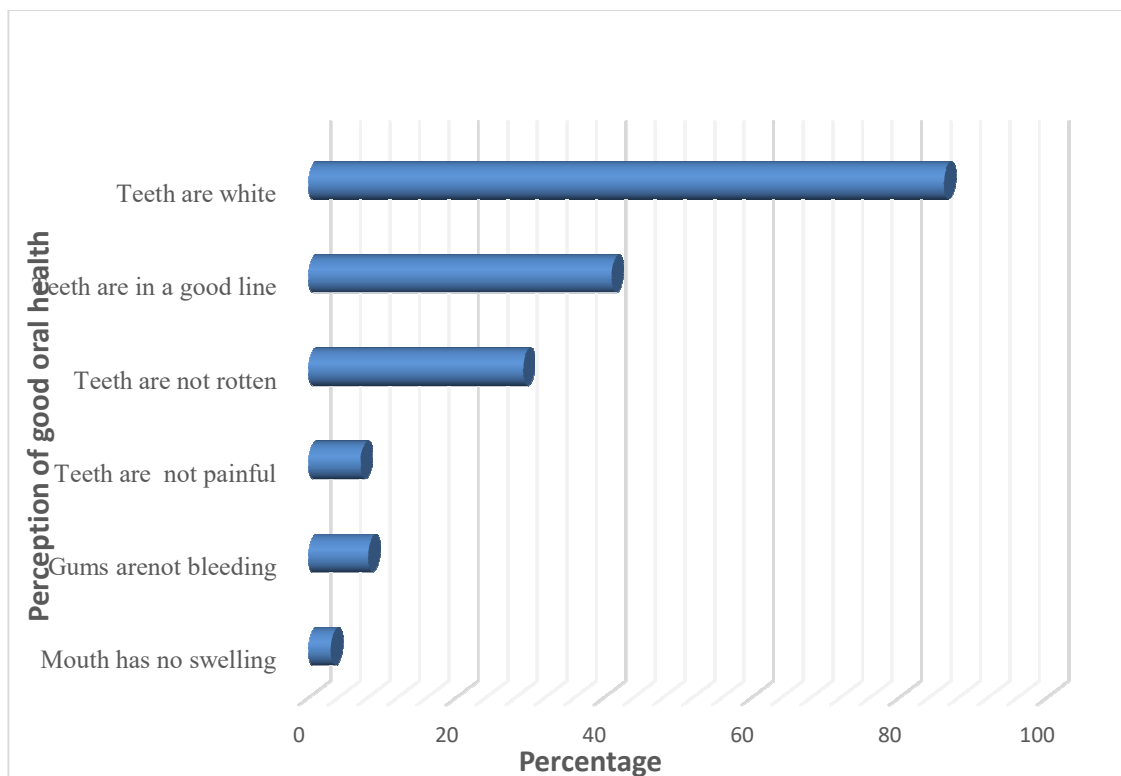
Source: Survey data, 2016

4.4 Oral health perceptions, beliefs and cultural practices

In line with behavioural theories of health services utilization, psychological constructs such as willingness (motivation) to seek healthcare is influenced by self-perceptions of well-being, disease severity and perceived susceptibility to disease. Perception is all about the way one regards understands or interprets a phenomenon. The caregivers were, thus, required to describe their perceptions of ‘good oral health’ and perceptions on the oral health status of their children.

4.4.1 Perceptions of good oral health

The respondents mostly based their perceptions of good oral health on aesthetics and appearances of the teeth rather than the absence of oral disease (Figure 4.2).



*Percentage is greater than 100% due to multiple responses

Figure 4.2: Respondents’ perceptions of good oral health (Source: Survey data, 2016)

The most frequently recurring description of good oral health was “teeth which are white”, followed by “teeth which are in a good line”, and “teeth which are not rotten”. The respondents seemingly embraced the aspect of self-worth in their own perceptions of good oral health. According to participants in the focus group discussions, the outward show of teeth gave them self-confidence during social interaction with others and at their places of work. They frequently stated their desire to have ‘clean, white, and evenly arranged teeth with no gaps in-between’ for themselves and their children. The following insight illustrates these perceptions that emerged from the caregivers’ focus group discussions at KNH:

When people have teeth that are rotten, they have to cover their mouths most of the time while talking. There is that notion that other people are looking and wondering why someone has stayed for so long without going to see the dentist (FGD, KNH).

The participants at one of the GCH focus group discussions stated it this way:

When we meet and talk to our customers and we have nice white teeth, it gives us the confidence and it helps us to be successful in what we do (FGD, GCH).

4.4.2 Perceptions of child’s oral health status (OHS)

A caregiver’s perception of their child’s oral health status is a strong determinant on whether the child will visit a formal health provider for oral healthcare. This study, therefore, required that the respondents describe their perception of the child’s OHS. The responses to this question, interestingly, yielded equivocal results. Nearly equal numbers of caregivers (29%) described their child’s OHS as good, and as poor (27%), whilst those who thought that their child’s OHS was fair were 25%; other perceptions of child’s OHS were, very good (17%) and don’t know (2%). These responses are illustrated in Figure 4.3.

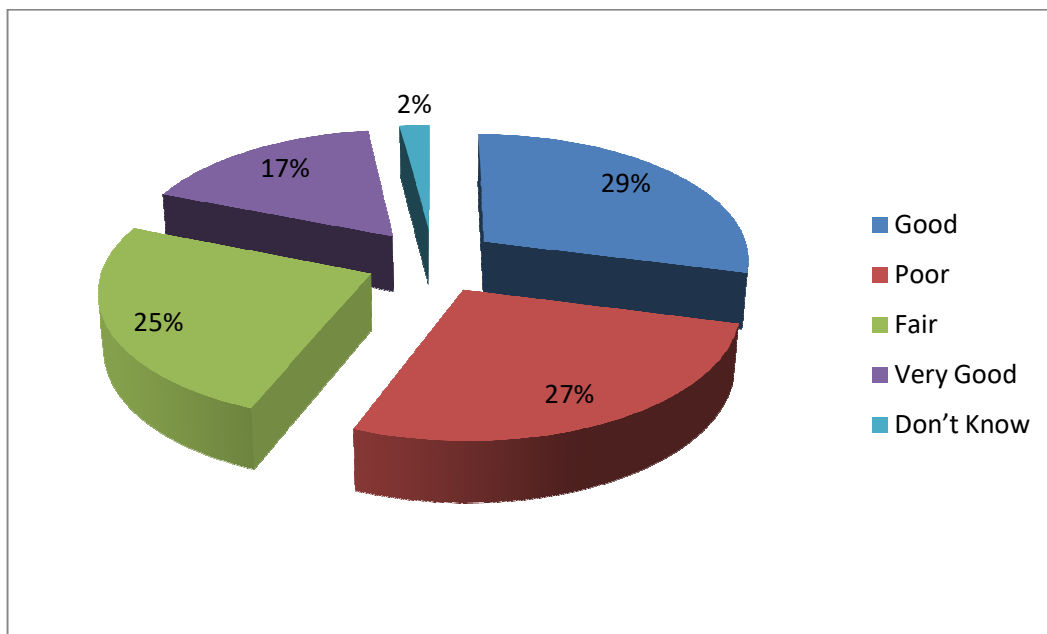


Figure 4.3: Respondents' perceptions of their child's OHS (Source: Survey data, 2016)

4.4.3 Rating of the child's OHS compared to peers

The respondents were further asked to rate the appearances of their child's teeth, contrasting them with those of other children they interacted with. They were expected to score their ratings from 'among the nicest' to 'among the worst'. It was clearly explained to them that the comparative ratings were to be made with the children's' peers at school or at home, and not necessarily those children who attended the HIV-care clinics. As presented in Table 4.3 below, the highest percentage (29%) of caregivers, rated the appearance of their children's teeth as average compared to their peers. Sixteen per cent rated them as among the best, while 23% rated them as better than average. The other ratings were, below average (22%), among the worst, (7%) and don't know (3%). These results suggest that respondents did not view their children's teeth to be very different in appearance from other children.

Table 4.3 Respondent’s rating of the child’s OHS

| Rating of OHS | Frequency | Percentage |
|----------------------|------------------|-------------------|
| Among the nicest | 36 | 16 |
| Better than average | 49 | 23 |
| Average | 65 | 29 |
| Below average | 48 | 22 |
| Among the worst | 16 | 7 |
| Don’t know | 7 | 3 |
| TOTAL | 221 | 100 |

(Source: Survey data, 2016)

4.4.4 Perceptions of dental caries

The oral health needs measures that create the demand to utilize oral healthcare are frequently based on perceptions of the severity of dental illness by the individual. Respondents in the current study appeared to view that having decayed or ‘blackish teeth’ was not a necessarily a serious illness but a normal occurrence among children with HIV/AIDS. The survey results presented in Table 4.4 indicate that more than half (58%) of the respondents attributed the cause of the disease to the use of ARV medication, 47% of caregivers were of the view that dental caries was caused by consumption of sugar, 44 % dismissed it as ‘just black marks that appear on the teeth’, while 42% viewed dental caries, more correctly, as rotting teeth. The other responses elicited from the respondents on dental caries were: dirty coloured teeth (38%), teeth that want to come out (25%), common problem in children (29%), due to poor eating (11%), infected by other people (15%), and don’t know (21%). These kinds of views which diminished the seriousness of dental caries as an illness greatly undermined the caregivers’ resolve to seek oral healthcare for their children.

Table 4.4: Respondents' perceptions of dental caries

| Perceptions | Frequency | Percentage |
|-----------------------------|------------------|-------------------|
| Comes from using ARV drugs | 128 | 58 |
| Occurs in families | 66 | 30 |
| Disease of taking sugar | 104 | 47 |
| Black marks on the teeth | 98 | 44 |
| Dirty, coloured teeth | 84 | 38 |
| Rotting teeth | 94 | 42 |
| Teeth that want to come out | 56 | 25 |
| Common in children | 64 | 29 |
| Poor eating | 24 | 11 |
| Infected by other people | 34 | 15 |
| Don't know | 46 | 21 |

*Percentage is more than 100% due to multiple responses

(Source: Survey data, 2016)

Some of the views on tooth discolourations were corroborated among participants in the focus group discussions, for example, the caregivers at the GCH focus discussion group stated:

The ARV medication helps us to maintain our health but it also gives us problems. One of the problems is that we get black colourations on our teeth, bad breath and mouth sores because of the drugs. If you look at the teeth of most of the children in this clinic, they have the same kind of discolourations, so we know that it is because of the medicines. It is not really a serious illness (FGD, GCH).

However, the caregivers at MCRH appeared to hold a different, seemingly more correct viewpoint, on causative factors of dental caries. They opined that dental caries in children comes about as a result of consuming sugary foods, and failing to brush teeth as often as was required. For these reasons, they attempted to instill commensurate home-care practices among their children to protect them from dental caries, but with some difficulties. The statement below

illustrates the challenges they face in instilling homecare practices to protecting their children from developing dental caries:

We know that sugary foods cause cavities. Every now and then we give our children sweets and biscuits because they really love them. Sometimes they get the sweets from their friends when we are away or they buy them with the money we give them to buy break at school, and they don't brush their teeth in the evening. It is quite a big problem (FGD, MCRH).

4.5 Dental pain and well-being of child

Children with HIV/ AIDS frequently suffer pain from decayed teeth and/or soft tissue infections which oftentimes affects their well-being and oral health quality of life. According to the findings of this study, nearly two-in-five (41%) of the children had suffered some form of dental pain or other oral illness. Among those children, three-quarters (75%) were reported to have suffered toothache, while the remaining quarter (25%) had experienced pain that was related to mouth infections, swellings or bleeding gums.

4.5.1 Frequency of dental pain and discomfort

The children were affected variously by dental pain and discomfort. Some of them were reported to have pain more frequently than others. According to the findings, the largest percentage of children (41%) experienced oral pain and discomfort 'sometimes', while others (35%) experienced oral pain and discomfort 'often', and 17% 'occasionally'. A small number of children (4%) experienced pain 'always' (Table 4.5). One must keep in mind that for this study, the respondents acted as proxies in reporting the children's dental pain and, therefore, the responses may be subject to some recall bias.

Table 4.5 Frequency of child’s dental pain or discomfort

| Dental pain or discomfort | Frequency | Percentage |
|----------------------------------|------------------|-------------------|
| Always | 4 | 4 |
| Often | 32 | 35 |
| Sometimes | 37 | 41 |
| Occasionally | 16 | 17 |
| Don’t know | 3 | 3 |
| TOTAL | 92 | 100 |

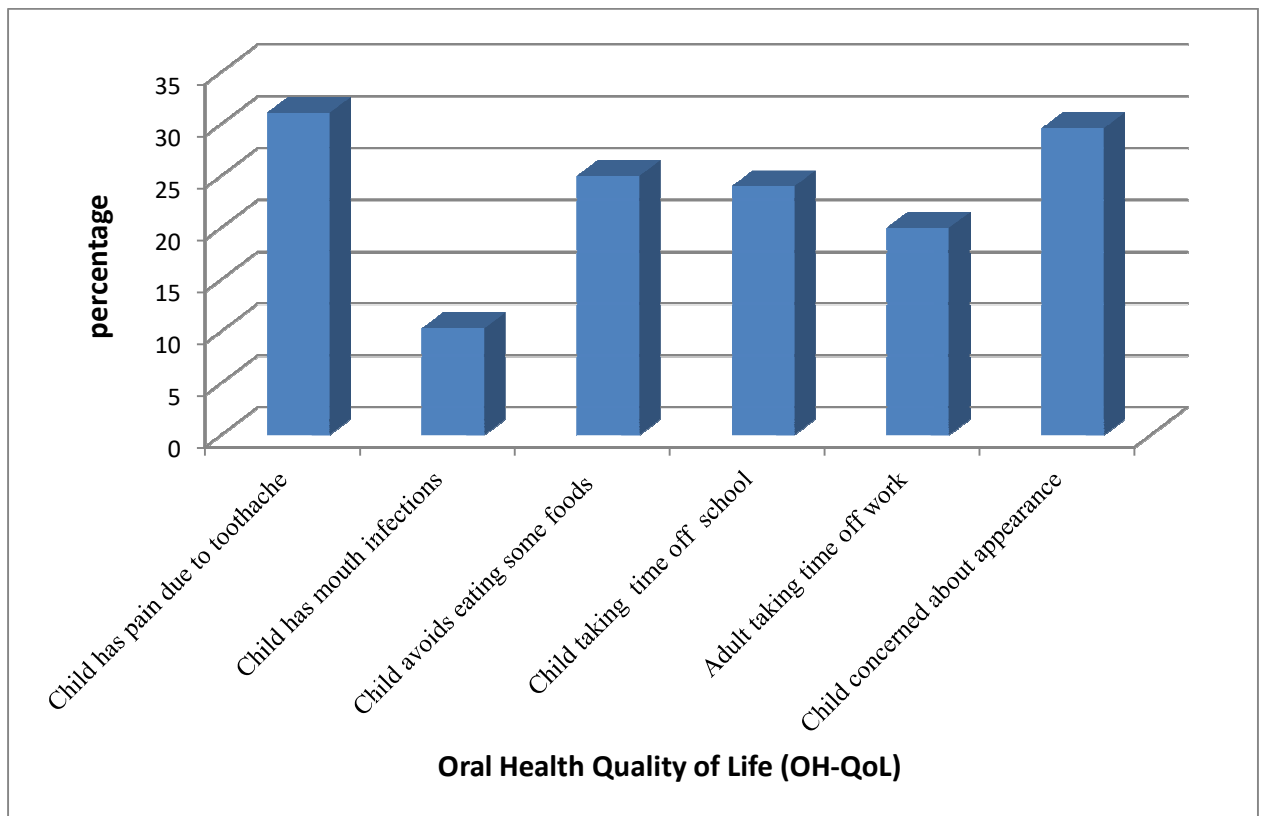
(Source: Survey data, 2016)

4.5.2 Child’s oral-health-quality of life (OH-QoL)

Diseases and disorders that occur in the mouth often disturb function and can affect the oral health quality of life and well-being of the child. Therefore, information was sought from the respondents on certain functional domains of their child’s oral quality of life. Besides the pain suffered from toothache (31.1%), and gum and mouth infection (10.3%), one-quarter (25%) of the children avoided eating certain foods because of discomfort from their teeth or mouth, 24% of them stayed away from school because of problems with their teeth or mouth, while 20% of the adults had taken time away from work or normal activities because of problems with their child’s teeth or mouth. About thirty percent (29.6%) of the children were reported to be concerned about the appearance of their teeth (Figure 4.4).

The survey instrument, however, did not measure all the functional domains normally associated with oral-health-quality of life such as, “satisfied with appearance”, “avoid smiling and laughing”, and “other children make fun of me”. This was largely because by design of the study, caregivers did the reporting as proxies for their children. Therefore, it was not possible to elicit such

responses directly from the children themselves. It is probable that where a chronic medical condition such as HIV/AIDS exists which comes with a myriad of other co-morbidities, psychosocial issues in the functional domain, unless remarkable, are unlikely to draw much attention from caregivers.



*Percentage is more than 100% due to multiple responses

Figure 4.4: Child's oral-health quality of life (Source: Survey data, 2016)

4.6 Oral health beliefs and cultural practices in oral healthcare

This aspect of the survey instrument was left unstructured to allow the respondents liberty to describe their oral health beliefs and cultural practices to some depth, while choosing their own words to express themselves. By doing so, the researcher was able to capture a real sense of the convictions that caregivers of children with HIV/AIDS have towards oral health and practices.

4.6.1 Tooth extraction is the only remedy for a painful tooth

According to the caregivers' beliefs, tooth extraction was the only '*quick and easy remedy*' for toothache. Therefore, to most of the discussants, the utilization of oral healthcare constituted no more than the removal of painful or 'bad' teeth. Thus, interestingly, the dentist was depicted as '*a doctor specialist in extracting teeth*'. Additionally, the caregivers strongly held the view that primary teeth in children were '*temporary*' and they would '*fall out*' anyway with time; consequently, treatment for them was unnecessary and wasteful of health expenditure. On the other hand, the permanent teeth were also believed to undergo '*natural ageing*' increasingly and eventually wear out completely. The participants in one focus group discussion stated their beliefs concerning the value of the first teeth in children in the following manner:

Children's teeth are temporary and they stay for a short time in the mouth. Why should we spend a lot of money having them treated when they will eventually fall out when they are ready? When our children have pain, we usually tell them to persevere, or we buy them a pain-killer from the shop. If the pain becomes too persistent, we take them to the dentist for extractions (FGD, GCH).

The caregivers themselves followed a similar pattern in treating their own dental pain. The initial remedy for toothache was usually to self-medicate using painkillers bought from the shops and/or *kiosks*. The caregivers mostly attended for formal healthcare services only when toothache

became unbearable. It was obvious that the caregivers had apathy and non-acceptance of any other forms of treatment for dental pain other than extraction of the offending tooth. Stated below is the oral healthcare-seeking behaviour of participants at the KNH focus group discussion.

At the start of a toothache we normally use painkillers which we buy at the shops or kiosks, but later on, the painkillers either stop working or the tooth becomes swollen, and then we are forced go to the dentist. The best treatment for painful teeth, of course, is to have them removed. If not, they will keep infecting each other. There are some of us who have tried to go for treatment with fillings, but the pain continues even after the filling is done, until the tooth is finally removed (FGD, KNH).

4.6.2 The use of traditional home remedies

The caregivers reported use of traditional and home remedies from time to time, especially among the older respondents. These remedies were usually in the form of local herbs or *mitishamba*, or sometimes they were in the form of powders. The caregivers who used these herbal treatments mainly did so as first-aid measures to relieve pain in the teeth or gums but when pain persisted, they resorted to seeking formal oral healthcare. According to the focus group discussants, the herbs were sourced from traditional herbalists who have knowledge passed on to them generationally, on the correct types of herbs and how to use them; the instructions were usually to smear them on the affected area in the mouth or to boil the herbs and inhale the steam. Additionally, the caregivers used a salty mouth gargle when they experienced sore gums; this was shared knowledge among them. The salty mouth rinses was seen to heal mouth sores and relieved gum pain. Some discussants further reported the regular use of salt and/or charcoal as substitutes for toothpaste, but mainly this was because they could not afford the cost of commercially produces toothpastes. From the perspective of the caregivers, traditional and home remedies were

reliable methods since advice on their use came from trusted sources. The remedies, they stated, were considerably less toxic and relatively inexpensive compared to the conventional products of oral health practices such as the mouthwashes, toothpastes and other oral medications.

4.6.3 'Nylon' teeth and other taboos

There were interesting beliefs and practices reported by the caregivers, surrounding the biological processes of teething in infants. They strongly believed that teething processes caused a child to suffer from fever and diarrhoea. When this happened to their children, the caregivers would make the decision to either seek biomedical care, or they resorted to using traditional and/or home remedies. Equally powerfully, caregivers held the belief that children oftentimes develop 'plastic' or 'nylon' teeth in infancy which, according to them, was a portal for carrying 'worms' that caused a child to have severe childhood illnesses which could become fatal. Treatment for 'nylon' teeth, they stated, was only found in the rural homes with traditional 'healers' who 'extracted' the plastic teeth using razor blades or other 'crude' instruments. Interestingly, these views emerged mostly from the women in the MCRH discussion group although, some of the caregivers held the alternative view that it was possible to use other home remedies to treat the 'plastic teeth' such as continually rubbing them with honey smeared on a piece of cloth until they fell off. So strong were these beliefs among some of the women that they avowed to have travelled to the village on the pretext of taking their child to visit his/her grandparents whilst secretly carrying out the traditional treatment against their spouses' wishes.

In other oral cultural beliefs the caregivers stated that having a new-born baby with teeth in the mouth, or having an infant whose teeth did not erupt in the correct order constituted a taboo for which the child had to be cleansed; otherwise, it was a bad omen for the family. These are the

views of participants at the MCRH and KNH focus groups, on infant teething experiences and other myths surrounding the eruption of teeth in infants.

It is normal for children to get diarrhoea when their first teeth begin to erupt. Some children also get other types of teeth which are not normal; they are nylon teeth that make them very ill because they keep worms inside. The children may die if the nylon teeth are not extracted. Expert women in the village remove these teeth very well with special knives. Mostly, the grandmothers advise us on where we can find them, or they can take the children to have the teeth removed (FGD, MCRH).

In some of our communities, children who are born with teeth in the mouth, or have teeth that are not growing in the right order are considered to be a bad omen for the family. Therefore, the child has to be cleansed from the evil spirit. This is done by slaughtering a goat. Here in town we do not usually practice this culture because most of us are Christians (FGD, KNH).

4.6.4 The influence of religious beliefs on oral healthcare

The social norms of religious beliefs and practices did not appear to have much direct influence on the oral health beliefs and practices of the caregivers. According to discussants in the focus groups, the Christian churches they attended played a minimal role in their oral health beliefs and practices. Instead, they facilitated medical camps from time to time, where oral health providers would be invited to visit and give advice on how to take good care of teeth or, sometimes, they would offer free basic oral health services. However, there were no special coercions from the point of faith on oral health practices and/or special healing prayers. Most of the women among the discussants were affiliated to the Protestant and Catholic churches.

4.6.5 Perceptions of HIV/AIDS stigma in oral healthcare

It is considered prudent that PLWHA should disclose their HIV-status to their oral healthcare providers to enable them receive oral healthcare that is pertinent to their condition. It was

important to find out whether caregivers disclosed their HIV-status to the oral healthcare provider that they visited. Figure 4.5 below indicates that more than half of the respondents (55%) did not voluntarily disclose their HIV-positive status to their oral healthcare providers, 35% of the respondents did not have a problem doing so, whilst 10% were unsure of the positions they held.

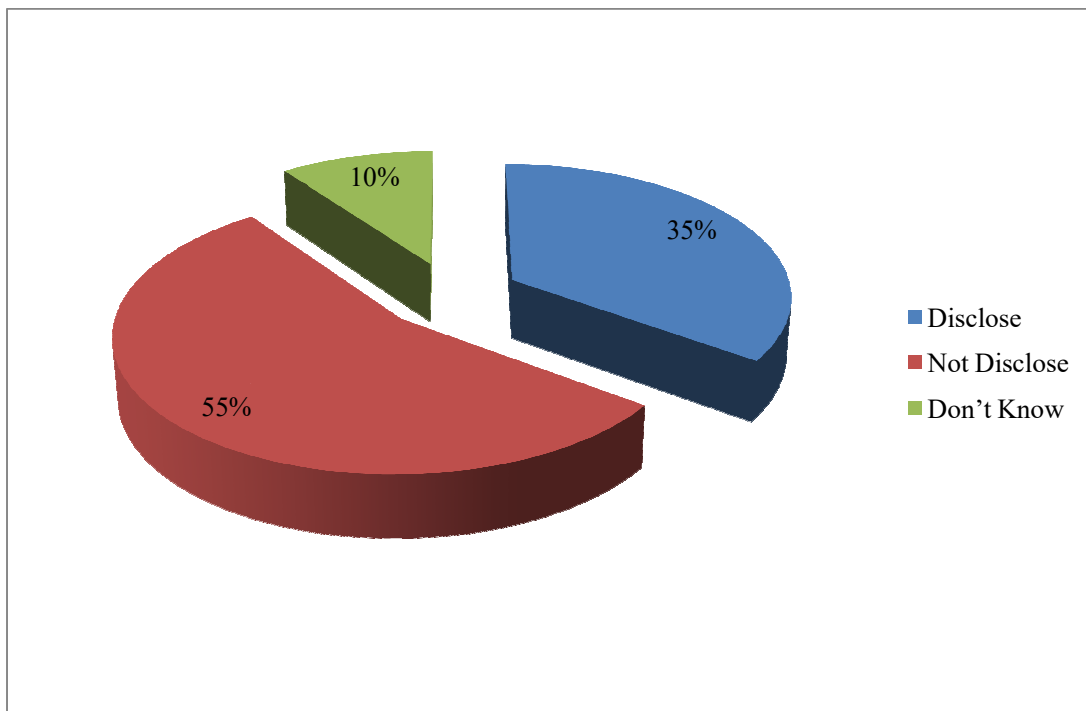


Figure 4.5: Disclosure of HIV-status to oral health provider (Source: Survey data, 2016)

The reasons given for non-disclosure strongly suggest that, among the respondents in this study, having HIV-positive status still carries a significant amount of stigma. There appeared to be a deep feeling of discrimination among the discussants in which they felt prejudiced against at other health settings. In their views, they were given inferior services as a result of their condition, and oftentimes, this perception deterred them from readily seeking oral healthcare for their children.

Participants in the focus group discussions at GCH expressed their perception of this discrimination in the following statement:

There is always discrimination against people like us. Even doctors and nurses in some hospitals treat us differently. As soon as we report our status, they start asking us so many questions, and their attitude changes. They may try to hide it, but we can see it in their eyes and from the way they behave towards us. They are judging us and they don't want to give us proper services (FGD, GCH).

It was also apparent from the discussants that they do not frequently make a connection between their oral health and general health, thus illnesses of the mouth, according to them, did not necessarily have anything to do with their medical condition. They illustrated these views in the following responses; *“dental illness is a different thing altogether and we don't see the connection”*, and *“disclosure just for the sake of it isn't necessary”*. The other views were that; *“HIV status is a personal issue”*, *“it is confidential”*, *“it is difficult”*, and *“disclosure could bring problems with employers and health insurance”*.

In summary, this chapter reports study findings on the perceptions of oral health among the caregivers, their beliefs and cultural practices in oral healthcare, and how these affect the utilization of oral healthcare for children with HIV/AIDS. Such constructs are key elements of social contexts in the patterned process of people making sense of their world, and the assumptions, expectations and practices they call upon in doing. For example, the diminished value of the primary teeth of children among the caregivers serves to reduce the oral healthcare demand for young children. Another instance is that the caregivers do not perceive dental caries to be an illness but rather, they believe that discolourations of teeth among the children results from the use of ARV medication. It is also clear that caregivers in this study subscribe to folklore and

other oral health myths surrounding the teething processes in infancy and, from time to time, they resort to the use of traditional and/or home-care remedies as first-aid measures to relieve pain and infection. These beliefs and practices prejudice the timely utilization of formal oral healthcare services for children with HIV/AIDS. It is also evident that the caregivers suffer from HIV/AIDS-stigma and they perceive discrimination while seeking oral healthcare services. The influence of religion on oral healthcare beliefs and practices, however, is minimal among the respondents in the study.

CHAPTER FIVE

UTILIZATION OF ORAL HEALTHCARE BY CHILDREN WITH HIV/AIDS

5.1 Introduction

This chapter presents findings of the study on the utilization of oral healthcare by children with HIV/AIDS with respect to the socioeconomic factors among their caregivers and structural factors of the healthcare system. The chapter begins by outlining the children's pattern of consumption of formal oral healthcare services, then goes on to describe the factors among their caregivers that determined this utilization of oral healthcare, and those that influenced the caregivers' selection of oral health facilities. Finally, the chapter reports on the caregivers' interactions with the oral healthcare system, and the way perception of quality of care influences caregivers' choice of oral health providers. The information contained in this chapter was derived from the survey, the focus group discussions, and the key informant interviews.

5.2 The utilization of oral healthcare

According to findings of the study, there was very poor utilization of oral healthcare for children with HIV/AIDS, with just over a quarter (28.38 %) of the children reported to have visited the dentist, or consumed any form of oral healthcare. Conversely, over seventy per cent (71.17 %) of the children had never visited any formal oral health provider for treatment or preventive care. Chi-square tests did not demonstrate an association between children's utilization of oral healthcare with caregiver's education level ($p > 0.05$), and/or caregiver's income ($p > 0.05$). This lack of a positive correlation may likely be explained by the minimal variation that existed within these variables, that is, the respondents mostly had similar education levels and household incomes within and across the hospital categories.

5.2.1 Reasons for child's visit to the dentist

An explanation was sought from the respondents on the main reasons why their child was taken for a dental visit. Pain was the biggest cue to action in seeking oral healthcare for children in the study. Among the children who had visited the dentist, 70% did so because they experienced pain, whilst others (22%) visited because of swelling or ulcers in the mouth. A small number of children (8%) visited the dentist for a checkup that was mainly recommended from school health-check visits.

5.2.2 Measures taken when the child experienced pain

It is often difficult to measure pain due to its subjectivity, especially among children. However, for the children who complained of toothache or discomfort in the mouth the caregivers reported taking certain measures. The most frequently taken measure by over two-thirds (66.3%) of the respondents was to visit a dental professional. Another 16.3% of the respondents bought medicine from the chemist, whilst 15.2% of them treated the toothache with home remedy. There were a small number of respondents (2.2%) who utilized the alternative services of traditional healers for their children's dental pain. Interestingly, participants in most focus group discussions claimed that women were the main decision-makers in the families regarding when, how, and from where to access healthcare for their children. Whenever their child fell ill they embarked on seeking medical help themselves to the best of their abilities, rather than wait for their spouses to advice. This is how discussants in the focus group discussions at GCH articulated this sentiment:

Mtoto ni wa mama. Akiwa mgonjwa, wewe kama mama lazima utafute juu na chini mpaka umpeleke akatibiwe. Mama ndiye anayejua uchungu ya mtoto (A child belongs to the mother. When they fall ill, you, their mother, must do all that you can to ensure that the child is attended to. A mother knows best the needs of her child) (FGD, GCH).

5.2.3 Period of child's visit to the dentist prior to the study

Almost two-thirds (62.5%) of the respondents reported that children had visited the dentist within the last 12 months of the study period, 25.3% between 12 and 24 months, and 6.0 % between 24 and 60 months prior to the study. A small number (2.3%), had visited the dentist over 60 months prior to the study, while 4% of the respondents could not recall. These findings suggest that the utilization of oral healthcare services among the children, while not regular or absolute, had improved considerably over the years leading to the study.

5.2.4 Treatment carried out at the child's dental visit

Tooth extraction was the foremost treatment carried out among the children who visited the dentist. Almost two-thirds (62%) of the children received this treatment, while very few (10%) had dental fillings carried out. The other forms of treatment were dental check-ups (11%), cleaning (7%), and medicines (8%). The high percentage of children who had tooth extractions carried out may have had this treatment influenced by delay in seeking care, or it was the preferred choice of treatment by their caregivers. The caregivers' testimony of their own utilization of oral healthcare was slightly better than that of their children, whence 48% of them had paid a visit to the dentist. They mostly (98%) had tooth extraction carried out as the preferred treatment alternative.

5.2.5 Timeliness in seeking oral healthcare for child

Timely seeking of treatment, most of the time, translates to early treatment of the disease and improved health outcomes. The timeliness of seeking oral healthcare may be influenced by several factors, *inter alia*, the perceived severity of the illness by caregivers. According to the

study findings, only 10.9% of the respondents sought treatment for their children within the first 1-2 days of the onset of pain, 23.9% of respondents waited for between 3 and 4 days, 30.4% waited for between 5 and 6 days, while another 29.3% of respondents sought treatment for their children after more than one week of the onset of pain. The remaining 5.5% respondents could not recall the timeliness of seeking oral healthcare for their children.

One key informant at MCRH opined that the reason why caregivers do not often seek timely treatment for their children is because they may not fully appreciate the extent of the child's pain, hence the delay in promptness of seeking treatment. This is how she stated it: *“You have to understand that it is not the mother who is suffering from pain, so they may not appreciate the full extent of the pain. They will keep sending the child to school, even with toothache until the day that the child is unable to sleep, then they rush the child for treatment”* (Nurse, MCRH).

5.2.6 Usual source of oral healthcare

The best practices in oral healthcare inform that children should have enrollment at the so-called ‘dental homes’ to facilitate a regular source of care. In this fashion the child's oral healthcare is likely to be delivered in a comprehensive, continuously accessible manner and result in optimal oral health outcomes. Unfortunately, this was not the case among the children in this study. Majority (93%) of the caregivers did not have a usual source of oral healthcare for their children; instead, visits to the dentist for the child were undertaken in an *ad hoc* manner, usually for symptomatic reasons such as a painful tooth, and from any oral health provider that was conveniently located to the caregiver. For these reasons, the caregivers in may be categorized as “emergency patients” who only attend for oral healthcare when they have pain. The data on patterns of the utilization of oral healthcare by the children are summarized in Table 5.1.

Table 5.1: Patterns on the utilization of oral healthcare by children with HIV/AIDS

| Variables | Category | Frequency | Percentage |
|--|------------------------------|------------------|-------------------|
| Utilization of oral healthcare by child | Yes | 61 | 28 |
| | No | 157 | 71 |
| | Don't know | 4 | 1 |
| Measures taken when child experienced toothache* | Visited dental professional | 61 | 66 |
| | Bought medicine from chemist | 15 | 16 |
| | Treated with home remedy | 14 | 15 |
| | Visited traditional healer | 2 | 2 |
| Reasons for child's visit to the dentist | Pain | 43 | 70 |
| | Swelling/ulcers | 13 | 22 |
| | Check-up/other | 5 | 8 |
| Period of last dental visit prior to the study | Within 12 months | 38 | 62 |
| | Between 12 & 24 months | 15 | 25 |
| | Between 24 & 60 months | 4 | 7 |
| | >60 months | 2 | 3 |
| | Don't know | 2 | 3 |
| Treatment carried out at child's dental visit** | Check-up | 7 | 11 |
| | Tooth extraction | 38 | 62 |
| | Dental filling | 6 | 10 |
| | Cleaning | 4 | 7 |
| | Medicine | 5 | 8 |
| | Don't know/other | 1 | 2 |
| Timeliness in seeking oral healthcare | Within 1 and 2 days | 10 | 11 |
| | Between 3 and 4 days | 22 | 23 |
| | Between 5 and 6 days | 28 | 30 |
| | After one week | 27 | 29 |
| | Don't know | 5 | 6 |
| Regular source of care for child | Yes | 206 | 93 |
| | No | 11 | 5 |
| | Don't know | 4 | 2 |

*92 children experienced toothache

**61 children visited the dental professional

Source: Survey data, 2016

5.3 Factors that constrain dental visits among caregivers

The study sought to learn about the constraining factors that caregivers face in the utilization of oral healthcare for their children. There were multiple responses to this investigation as presented in Table 5.2.

Table 5.2: Factors that constrained dental visits among respondents

| Constraining factor | Frequency | Percentage |
|-----------------------------|------------------|-------------------|
| It is too expensive | 96 | 43.2 |
| It is not necessary | 40 | 18.0 |
| Child has no pain | 47 | 21.2 |
| I have no knowledge | 42 | 18.9 |
| There are few dentists | 13 | 5.9 |
| I have no time | 29 | 13.1 |
| Dental treatment is painful | 16 | 7.2 |
| I don't know | 15 | 6.8 |
| ** 'Others' | 11 | 5.0 |

*Sum is more than 100% due to multiple responses ***'Others' included laziness, ignorance, and 'assumption'

(Source: Survey data, 2016)

The most frequently cited constraint (43.2%) was the perceived high cost of oral health services. The other reasons given were that: it was not necessary (18.0%); there was no pain (21.2%); we have no knowledge (18.9%); there were few dentists available (5.9%); there is no time (13.1%); and dental treatment is painful (7.2%). The responses above were corroborated during the focus group discussions with the caregivers. Most of the participants in the group discussions were in agreement that affordability of oral healthcare services was one of the main reasons that constrained utilization of oral healthcare. They mostly stated that they were not able to sustain regular use of oral healthcare for their children because money was scarce and not always

available when required. The consensus opinion of the focus group discussions at KNH regarding affordability of oral health services was as follows:

Dental services are very expensive. Sometimes the doctor tells us that it will cost KES 500 to pull out your child's tooth and the child may have 2-3 teeth that need treatment. There are many times that we don't have that money. Therefore, we have no choice but to wait until the money is available. 'Wajua, hii kazi yetu ni ya kubahatisha (You know, our livelihood depends on luck) (FGD, KNH).

There was also the input of one key informant (KI) on financial constraints that some caregivers may face as a result of having to care for large families. According to her, financial burdens may be occasioned by having to take on additional responsibilities of caring for orphaned children who have lost their parents from the ravages of the disease. *"The financial burden of extended families that we see here is a reality. Some caregivers have to cater for all of the adopted child's physical and educational needs and, sometimes, attending for oral healthcare is not a priority unless the child is suffering from severe toothache"*(Nurse, MCRH).

The responses also suggest that there is fairly low oral health literacy among the caregivers which ultimately affects utilization of oral healthcare services for their children. The caregivers' perceptions of utilizing oral healthcare are limited to the relief of pain from an offending tooth, with no reference to employing dental check-ups and/or preventive oral healthcare services. Participants in the focus group discussions were in general agreement that lack of knowledge and information on oral health caused them to utilize oral healthcare only when their children experienced toothache. This is what the discussants in one focus group stated:

We don't know that we can take our children to visit the dentist just for a check-up so we only go when the child experiences pain. There is no-one telling us these things. How come the health workers here don't tell us much about dental health? Sometimes we don't even know where to go for treatment so we tell our doctors to prescribe medicine to relieve the pain (FGD, MCRH).

It was further apparent that lack of knowledge and information on oral health also existed among health workers at the HIV-clinics. They too acknowledged that they lack sufficient knowledge on oral health to disseminate to their patients. This is how one KI stated her concern: *“Even we, as health workers at this clinic lack the correct information to give our patients on oral health and utilization of oral healthcare. Therefore, we can’t make recommendations to our clients which we ourselves are not practicing”* (Counselor, KNH).

It was also the opinion of a health worker at KNH that caregivers frequently view dental illness as a cosmetic rather than a serious illness *vis a vis* their HIV/AIDS condition. As a result, they give less priority to oral healthcare. This is what she stated:

These patients generally view dental diseases as not being as serious as HIV/AIDS; therefore, they do not view it as a priority. Sometimes the appearance of the child’s teeth may be an issue, but not always. The patients are more keen on taking medications to sustain their health so dental healthcare ceases to be a big issue to them (Social worker, KNH).

Some women stated that they did not take their child to the dentist because of pain they had themselves experienced, during tooth extraction. A few of the caregivers feared that, in some instances, death could occur as a result of a visit to the dentist. They claimed to have observed this happen to some of their friends and relatives who died whilst undergoing tooth extraction.

5.3.1 Health insurance and payment for health services

The ability to take up health insurance by an individual is, to a great extent, tied to having a regular source of income. Those individuals with irregular or low-income muscle are *unlikely* to have health insurance, are less likely to utilize healthcare and, when they do, it is liable to be imposed by limitation in the kind of treatment they can receive, and the facilities from which they

can access care. Thus, it was important for this study to seek information on the respondents' health insurance status and how they paid for oral health services for their child.

5.3.2 Respondents' health insurance status

Figure 5.1 shows that more than two-thirds (68%) of the respondents in the study did not have health insurance to facilitate access to medical and/or dental services. On the other hand, 21% utilized their employer's or spouse's health insurance, and only 8% had a personal health insurance. Cross-tabulation of data did not establish association between having health insurance and utilizing oral healthcare ($p > 0.05$). Although this might seem to suggest that lack of health insurance among caregivers was not a restricting factor in utilization of oral healthcare, it must be noted that majority of the caregivers did not have health insurance in the first place, thus, this variability was greatly narrowed down. This may not be the correct interpretation of the finding.

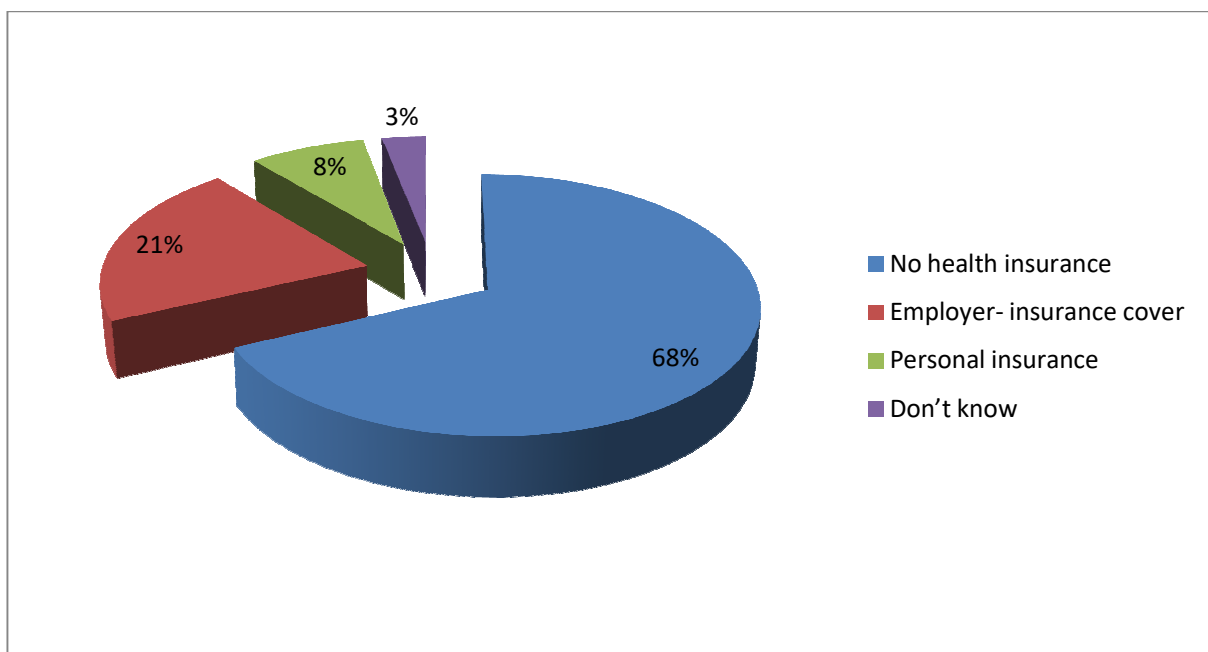


Figure 5.1: Respondents' health insurance status (Source: Survey data, 2016)

5.3.3 Reasons for not having NHIF insurance

Most national governments, Kenya included, have put in place social health insurance (SHI) aimed at improving access to healthcare for their citizenry. However, with only 18% of the respondents having been registered with the National Hospital Insurance Fund (NHIF), this was an indication of poor participation in the national social insurance. The most recurring reason (31.3%) was that caregivers did not know much about the Fund. Besides that, there were responses like: we cannot afford it 29.1%; payment is too high 27.5%; I am not working (23.1%); it covers only civil servants (15.9%), and queries on cover for dental treatment (12.6%). These responses (Table 5.3) suggest that there is insufficient knowledge and sensitization about NHIF, compounded by the caregivers' own perception of their inability to afford payment which they associate with having irregular incomes from informal employment.

Table 5.3: Respondent's reasons for not having NHIF insurance

| Reasons | Frequency | Percentage |
|---------------------------------|-----------|------------|
| We don't know about it | 57 | 31.3 |
| We cannot afford it | 53 | 29.1 |
| Payment is too high | 50 | 27.5 |
| My husband has refused | 27 | 13.7 |
| It covers only civil servants | 29 | 15.9 |
| Does it cover dental treatment? | 23 | 12.6 |
| I am not working | 42 | 23.1 |
| I need more information | 25 | 13.7 |
| I don't know | 14 | 7.7 |

*Sum is more than 100% due to multiple responses

(Source: Survey data, 2016)

The participants in focus group discussions stated that whereas they may be aware of the benefits of the Fund, they had reservations about its laborious operations which included travel to accredited health facilities, finding an oral health provider who would accept to treat them on the NHIF cover, and penalty for default on payment. Below, is a consensus statement on how discussants at the focus groups in KNH perceived some of the problems of NHIF:

Health insurance is good and we know that it can help us when our children fall sick or whenever we have a medical predicament. The problem is that NHIF does not give cover for dental treatment unless you are a civil servant; we are usually turned away. In addition, when someone skips payment for even one month, they can't get the services and they lose everything (FGD, KNH).

5.3.4 Mode of payment for oral healthcare services

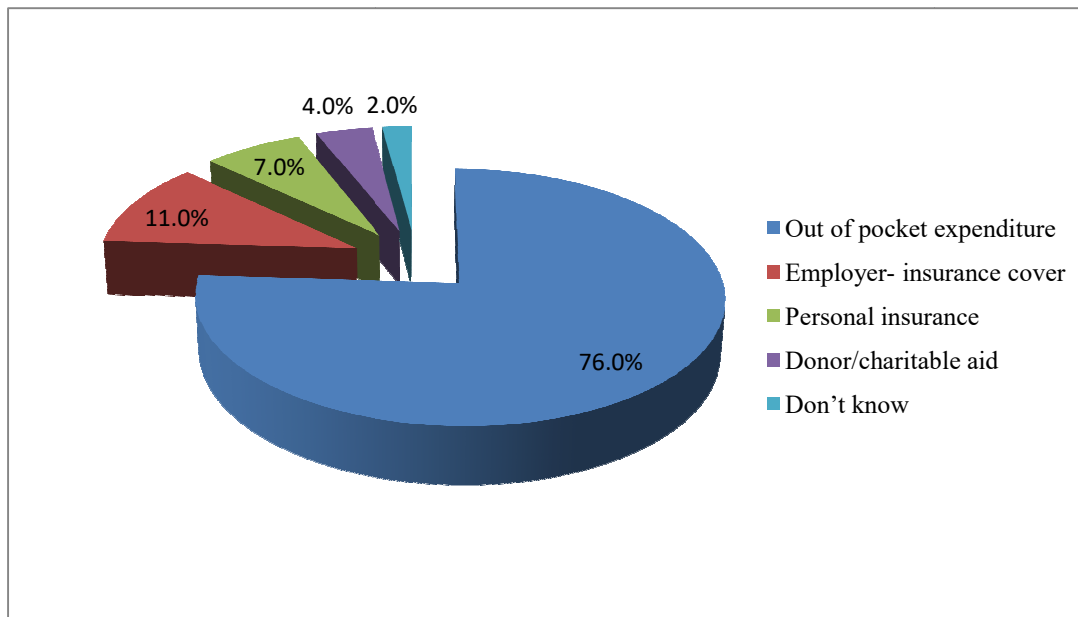


Figure 5.2: Payment for oral health services by respondents (Source: Survey data, 2016)

While dental health insurance does not remove all the financial barriers to needed services, it enables people to obtain some amount of dental care. On the other hand, high out-of-pocket spending frequently prevents them obtaining the necessary services in a timely manner. According to the results presented in Figure 5.2, the mode of payment for oral health services by about three-quarters (76%) of the caregivers who accessed oral health services for their children was from 'out-of-pocket' expenditure. Those who paid through employer insurance were 11%, personal insurance 7%, while 4% paid through donor/charitable aid.

It is highly probable that the out-of-pocket mode of payment was an additional obstacle to utilizing timely oral healthcare for children with HIV/AIDS among their caregivers. The opinion of one KI at KNH was that caregivers were more likely to access HIV-care clinics more readily because medical services were offered *free of charge* at these clinics and caregivers did not have to go into their pockets for any payment. This is how he put it:

The patients who come to the HIV-care clinics are attended to free of charge, inclusive of consultation, lab tests and medicines. The caregivers are used to that; therefore, they shy away from seeking dental services because of having to pay for these services from their pockets (Pharmacist, KNH).

5.3.5 Affordability of oral healthcare services

It was important to find out the respondents' perception of the affordability of oral healthcare. The results presented in Figure 5.3 show that about thirty-two per cent (31.5%) of the respondents rated the user cost of oral healthcare services as very expensive, 46% rated them as expensive, whilst only 17.5% rated them as affordable. A few (5%) of the respondents did not give any opinion. When people perceive a health service to be *unaffordable* they either avoid using it altogether or, they identify other alternatives.

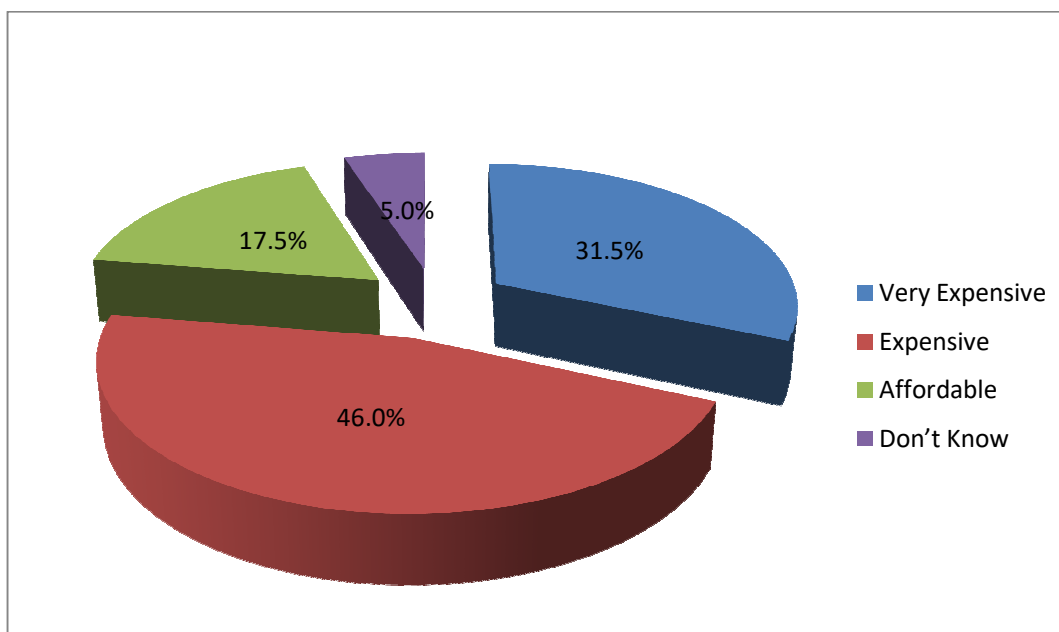


Figure 5.3: Affordability of oral health services by respondents (Source: Survey data, 2016)

During the focus group discussions, participants concurred that the high cost of oral healthcare frequently delayed timely visits to the oral health provider. It also made *tooth extraction* the preferred choice of treatment for the caregivers and their children because it was the cheaper option of dental care. For some of the caregivers, when their permanent teeth were extracted they were unable to afford replacement of the lost natural teeth. These views were strongly supported by one KI who lamented the lack of safety nets for caregivers which might assist them to access affordable oral healthcare for their children. The statement she made on affordability of oral healthcare services for the caregivers was as follows: *“Most of the women who visit our clinics consider dental healthcare to be very expensive. It is made worse because most insurance companies do not offer coverage for dental treatment, so the women have to pay for their child’s treatment from their pockets and oftentimes, they can barely afford it”* (Counsellor, GCH).

The study findings suggest that, as a result of caregivers being able to access free medical care for HIV-related illnesses, they were not willing to spend money on other health services offered outside the HIV-care clinics. One of the KI at KNH stated her sentiments on the same, in the following manner:

When caregivers source health services away from here, including oral healthcare, they have to pay consultation fees and other expenses. A few of them can actually afford it but even then, when they have drugs prescribed from other hospitals, you see them coming to collect the drugs from here because they are used to getting them free (Clinical officer, KNH).

Another KI at GCH was of a similar view that, caregivers feel an entitlement to free oral healthcare in much the same way that they receive free medical services at the HIV-care clinics.

This was her statement on the caregivers' sense of entitlement:

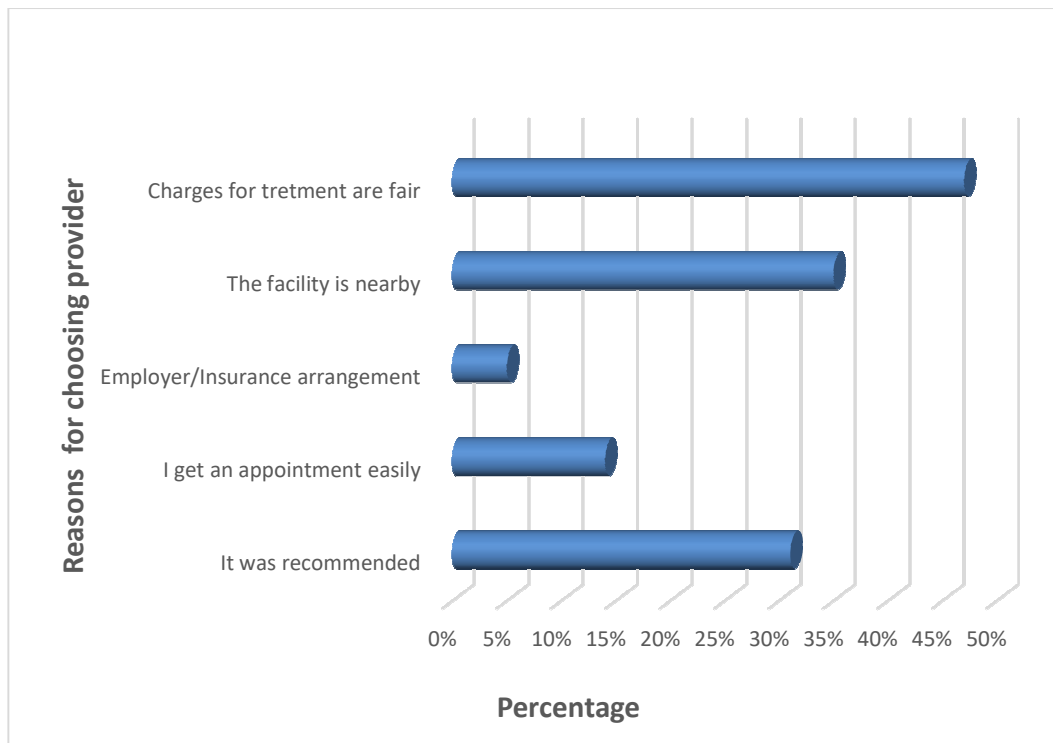
We give every aspect of HIV-support in these clinics free of charge. However, we are not able to provide specialized treatment procedures such as X-rays or dental care, therefore, for such cases we refer the patients outside. When we tell the women they ask, 'is it free'? When we tell them that it is not they tell us, 'I will go another day'. I doubt that they go because you can just see that they expect treatment to be free (Doctor, GCH).

5.4 The healthcare system and utilization of oral healthcare

The structural factors of the healthcare system are said to shape the individual's cost-benefit analysis of seeking healthcare. The number and distribution of dental clinics and their capacity to provide care whether, for example, the health facility offers services on weekends or evenings, proximity of the facility, financial and opportunity costs of travel to the facility, and the quality of care such as waiting time and attitude of healthcare providers, are all recognized as important structural factors that influence the utilization of healthcare. It was important for this study to

understand the factors that influenced caregivers' choice of health providers, therefore, the respondents were asked to specify their reasons for selecting particular oral health providers for the children's oral healthcare. There were multiple responses which are recorded in Fig 5.4. The most outstanding reasons were: perceived 'fair' user cost of treatment (47%); the proximity of the health provider to where they live (35%); and recommendation from others in their social networks (31%).

5.4.1 Choice of oral health service provider



*Percentage is more than 100% because of multiple responses

Figure 5.4: Reasons for choosing oral health service provider (Source: Survey data, 2016)

For caregivers in this study, the lay referral network system appears to play a significant role in influencing their selection of oral health providers. They appear to rely on word-of-mouth consultations and interchanges of information about the quality of care of the service providers.

The participants in one focus group discussion were in agreement that it was important to share health information among each other. This is the collective statement that emanated from the focus group discussions at KNH:

It is very important for us women to share experiences that help one another. We usually try to look for someone who has a medical problem that is similar to ours and then we consult them. For example, many of us are here because we were advised that this was the best clinic for HIV-care. If we looking for advice on dental care, our family members tell us where to go for proper treatment because having your teeth taken out in some of the dental clinics is very painful, so we avoid going there (FGD, KNH).

5.4.2 Distance travelled to oral health facility

The distance to oral healthcare facilities, or service location appeared to have a bearing on the selection of oral health provider for the caregivers. The highest percentage (29%) of respondents travelled short distances of 1-5 km from their homes to the oral health facilities of choice to access oral healthcare for their children. The modal range of distance travelled (29%) was 1-5 km, followed closely by 6-10km (27%). Nonetheless, some respondents (19%) travelled a distance of more than 15km to access oral healthcare (Table 5.4).

Table 5.4: Distance from home to oral health facility

| Distance (km) | Frequency | Percentage |
|----------------------|------------------|-------------------|
| >1km | 12 | 9 |
| 1 to 5km | 39 | 29 |
| 6 to 10km | 36 | 27 |
| 10 to 15km | 17 | 13 |
| More than 15km | 25 | 19 |
| Don't know | 4 | 3 |
| TOTAL | 133 | 100 |

(Source: Survey data, 2016)

The results imply that caregivers are likely to utilize service locations that are geographically proximal to where they live to access oral healthcare services. However, there was no association found between distance travelled by caregivers and utilization of oral healthcare ($p > 0.05$). The discussants in the FGDs were in agreement that they frequently chose oral health providers that were located nearby. To them, this was convenient because it precluded long travel distances to obtain the services they required and, also, this did not interfere much with their day-to-day income-generating activities. According to them, one could easily hurry to the oral health provider when they had a dental emergency rather than having to travel long distances to access care. This is how the discussants in one group stated the conveniences of having oral healthcare facilities located close to them:

The reason why we select dental clinics which are nearby is because the short distances to the clinic are convenient for us. Some of the dental clinics we visit are located at the shopping centres or just a short distance from where we live. When we get a toothache, we can quickly rush there, get treated and go back to work without wasting a lot of time. Another reason is that we don't require fare to reach the nearby dental clinics (FGD, KNH).

Several key informants were in agreement that long travel distances to a health facility, in many instances, required extra costs in transportation and also increased time spent away from work. This added to the total cost of utilizing healthcare services. The social worker at GCH had observed that caregivers frequently missed appointments because of lack of transport and the inconveniences of travel to far-located health facilities. This was his statement:

Many of our patients come from Eastlands, sometimes even further out of town. Having to travel long distances from their homes to the hospital can be a real challenge. Quite often, caregivers miss their appointments here because of the distances they have to travel and lack of transportation. They often say they have no fare, even when their appointments are spaced 3-4 months apart, or they say they have no one to leave their businesses with (Social worker, GCH).

5.4.3 Mode of transport to oral health facility

The mode of transport to oral health facilities is another important consideration in utilizing oral healthcare, particularly because it bears additional cost of travel to those seeking care. The use of public means was the commonest mode of transport reported by the respondents in this study (Table 5.5).

Table 5.5: Mode of transport to oral health facility

| Mode | Frequency | Percentage |
|----------------------|------------------|-------------------|
| Walk | 43 | 32 |
| Matatus/buses | 48 | 36 |
| Motorbike | 11 | 8 |
| Matatus & Motorbikes | 13 | 10 |
| Private Car | 8 | 6 |
| Taxi | 10 | 8 |
| TOTAL | 133 | 100 |

(Source: Survey data, 2016)

The results indicate that 32% of the respondents walked from their home to the oral health provider of their choice. Thirty-six per cent of the respondents used *matatus* and/or buses, 8% used motorbikes, also known as *boda-bodas*, 10% combined the use of *matatus* and *boda-bodas*, while 14% used private means of transport of which 6% were private cars and 8% were privately hired vehicles. The participants in the focus group discussions were in agreement that it was important to choose oral health providers who were located nearby because of transport costs, and the inconveniences of mode of travel when they were taking young children to hospital. The participants in the focus groups at MCRH had to say about the conveniences of nearby service locations for oral healthcare:

The issue of looking for fare makes it very expensive for us to access healthcare. It is also cumbersome to have to travel very far. Sometimes we have to board two or three 'matatus' to reach the hospital and that becomes very tedious especially when we are taking young children to the hospital. If we have a clinic nearby where we live, we can have our teeth extracted without much effort on travel and we prefer that. It makes things much easier for us (FGD, MCRH).

A doctor at GCH echoed the views of the participants and stated: *"The cost of transport is a major problem for many women who come here. Some of them have to save for up-to four months to ensure that they have transport to attend for their next appointment. There are also the inconveniences, for example, the 'matatus' drop them at the main road and then they have to use motorbikes to reach the clinic, carrying their children"* (Doctor, GCH).

However, it was observed that, whilst caregivers were unwilling to incur transport costs and/or travel inconveniences to access oral healthcare, they travelled much longer distances to access HIV-related medical care at facilities located much farther away from their homes.

5.4.4 Categories of oral health providers

The respondents visited various categories of oral healthcare providers to access oral healthcare when their children experienced dental pain. More than half (57.1%) of the respondents accessed oral healthcare from private dental clinics rather than public or government health facilities; others 19.5% visited government/public facilities, 6.1% private hospitals, and 15.0% mission/charitable clinics. A very small number of respondents (1.5%) sought oral healthcare from traditional herbalists for their children (Table 5.6).

Table 5.6: Categories of oral healthcare facilities visited

| Category of facility | Frequency | Percentage |
|------------------------------|------------------|-------------------|
| Government/public hospitals | 26 | 19.5 |
| Private hospitals | 8 | 6.1 |
| Private clinics | 76 | 57.1 |
| Mission/charitable hospitals | 20 | 15.0 |
| Herbalist | 2 | 1.5 |
| TOTAL | 133* | 100 |

* No of children and caregivers who had visited the dentist

(Source: Survey data, 2016)

It became clear during the focus group discussions that the type of private dental clinics visited by the caregivers were small individually-owned dental clinics located within the proximities of their neighbourhoods. The caregivers perceived the cost of services at these clinics to be more affordable. The clinics were also conveniently located nearby; they had long operating hours and did not require that one should make an appointment prior to visiting. In addition, the caregivers required little or no transport to access these facilities. The participants in one of the focus groups discussions summarized these conveniences in the following manner:

The small private clinics are convenient for many reasons. They are located very near where we live and we easily access them when we require treatment. They are convenient for our children as well. The children first go to school, then we take them there later in the evening because the clinics open for long hours. Furthermore, they are not very expensive; they charge KES 100-300 for tooth extraction for children. I think most of us can afford that (FGD, GCH).

5.5 Perceptions of quality of care

The perceptions of quality of care at health facilities are frequently measured by an individual's level of satisfaction with the non-medical aspects of health services, as well as their assessment of the attitude of the health workers at the health facility. Oftentimes, this determines whether the individual will return for treatment at the same facility in the future. The study explored the caregivers' perceptions of quality of care at the oral health facilities they had visited.

5.5.1 Satisfaction with clinic opening hours

Most (95%) of the respondents who utilized private dental clinics reported that the facilities opened and closed conveniently for them compared to the 56% of them who reported on the shorter opening hours at public facilities. The discussants were in agreement that the long opening hours at the private clinics, which included weekends, accorded them access to oral healthcare at their convenience, and especially that of their children. These are the insights that emerged from participants in one of the focus groups discussions. They stated thus:

At the private dental clinics, our children don't waste time away from school. The clinics open up to late in the evening, even up to 10.00 pm, so the children can first attend school. We can also take them for treatment on Saturdays unlike the dental clinics in government hospitals which don't open on weekends, and even if you reach there at 3.00 pm, you are sent away because they close early (FGD, MDH).

5.5.2 Satisfaction with waiting time

Waiting time is one of the most frequently mentioned concerns of patients and parents when they visit a health facility, particularly those patients who have less urgent and non-urgent problems. It was, therefore, important to gauge how much time caregivers usually spent at the oral health

facilities that they visited. The findings presented on Table 5.7 below indicate that about a half (46%) of the respondents experienced a waiting time of 0 to 2 hours at the oral health facilities they visited, 39% of waited for 1 to 2 hours, whilst 14% waited for between 2 and 4 hours. Only 1% of the respondents reported to have spent more than 4 hours before accessing treatment. The longer waiting times of 3 to 4 hours were particularly noted at the government or public health facilities, in contrast to the average waiting times of 1 to 2 hours at the private dental clinics.

Table 5.7: Waiting time at oral healthcare facilities

| Time (hours) | Frequency | Percentage |
|---------------------|------------------|-------------------|
| 0-2 | 61 | 46 |
| 1-2 | 52 | 39 |
| 2-4 | 19 | 14 |
| >4 | 1 | 1 |
| TOTAL | 133 | 100 |

(Source: Survey data, 2016)

Long waiting times at the public health facilities, according to the views of the discussants translated to loss of income from time away from their places of work. The participants in one focus group opined that one needed to have a ‘friendly’ insider to assist one access speedy care at public health facilities. This is what they said:

When we make the decision to visit public health facilities, it is because we know someone there who will help us to be seen quickly; otherwise we can waste the whole day there, and our work suffers. The health workers at public hospitals can be very unhelpful when you don't know anybody. That is why many times we prefer to look for some money and go to the private clinic when we are not very sick (FGD, KNH).

5.5.3 Satisfaction with cleanliness and maintenance

One of the areas that can impact the way a hospital rates among consumers is their perception of cleanliness at the health facility. In this study, both categories of health facilities (private and public) were perceived to have acceptable standards of cleanliness, although caregivers' perceived cleanliness to be better at the private dental clinics than at government/public facilities. More than two-thirds (68%) of the respondents reported cleanliness at the private health facilities to be very good, 30% reported them as good, and only 2% of reported them as average and below. On the other hand, the public oral health facilities had ratings of 44% very good, 32 % good, and 24 % average and below (Figure 5.5). The consensus view held on cleanliness by participants in the focus group discussions at MCRH was as follows:

The dental clinics that we have visited in both private and public hospitals are usually quite clean. Even the public hospitals are well maintained although you can see that the facilities are old, and some of them are broken down. Of course the facilities at the private clinics are always better (FGD, MCRH).

5.5.4 Satisfaction with oral health services

Satisfaction with health services oftentimes influences the further uptake of services by consumers who visit the health facility. The ratings for satisfaction with oral health services were better at the private dental clinics, where 62% of the respondents rated them as very good, 29% as good and 9% as average and below, while those at public facilities were rated at 28% very good, 38% good and 34% average and below (Figure 5.5). The figure illustrates high ratings of patient satisfaction at the private oral health facilities, with a few extremes on the lower end of the scale, while the ratings for the public facilities were mostly centered at average. This trend was observed in all three parameters of cleanliness, service and health worker attitudes

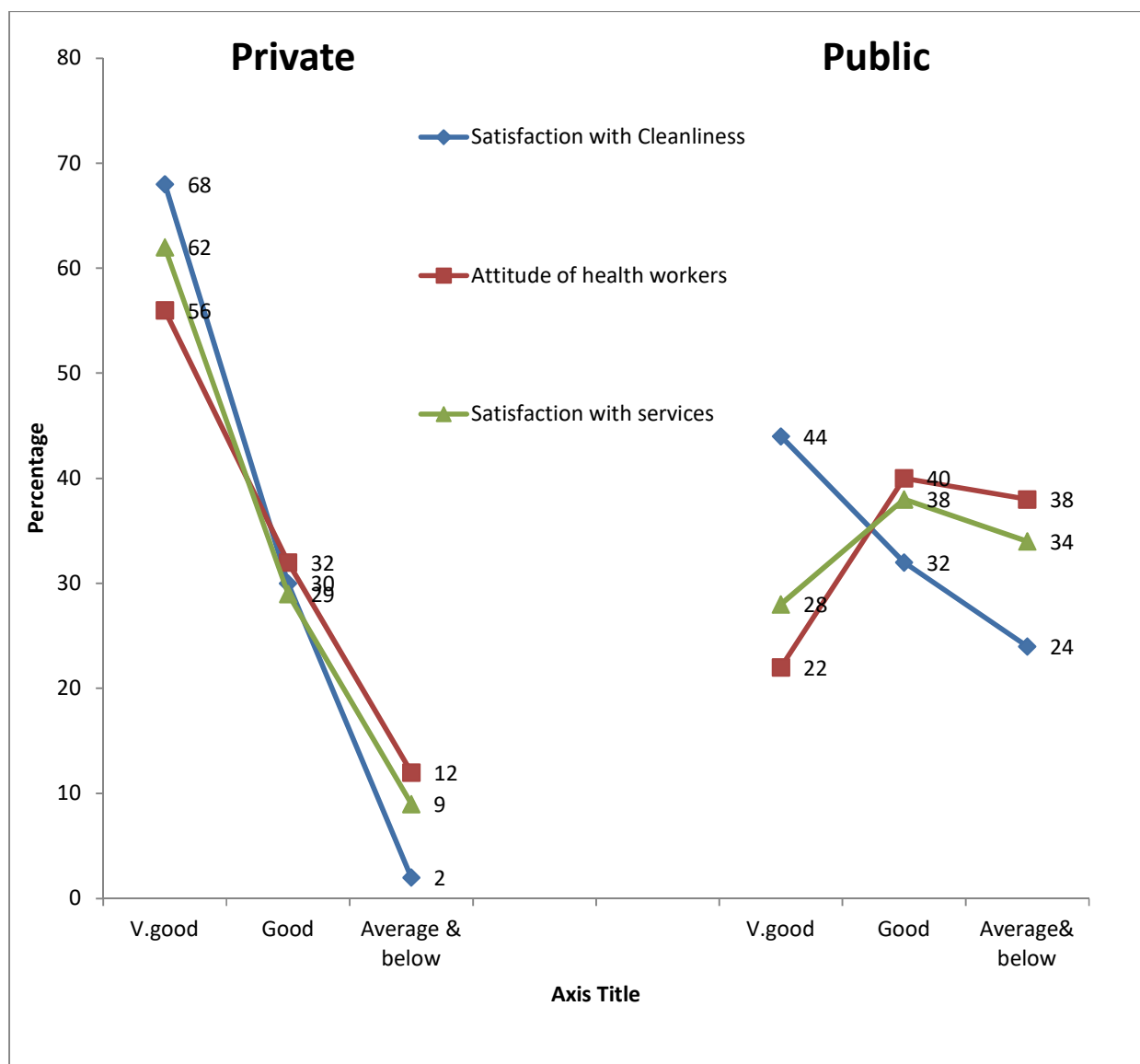


Figure 5.5: Respondent’s ratings on cleanliness, services and health workers’ attitudes at private and public oral health facilities (Source: Survey data, 2016)

The most outstanding aspects of service delivery at the private clinics according to participants in the focus group discussions, was the speed and efficiency with which they received services, and the availability of medicines and other facilities for treatment. In contrast, services at the government/public health facilities took a much longer time because of long queues which were

found at these institutions. The long queues at public hospitals, once again, translated to lost opportunity of being away from work. This is what participants in the focus group discussion at MCRH said about the long queues at public health facilities:

There are always long queues at public hospitals. Sometimes we are forced to go to private health facilities to avoid the long queues. At the private hospitals, they attend to patients quickly and the medicines are available right there. In public hospitals we stay for too long in the queues, sometimes for consultation, lab tests or medicines (FDG, MCRH).

One of the KIs at KNH shed light on the possible causes of long queues at public hospitals which oftentimes deterred patients from using these facilities. He made references to the processes and bureaucracy at public hospitals which tended to be long and tedious. This is what he stated:

It is quite tedious for patients to access care here at Kenyatta Hospital. They go through several processes that just take too long. They have to queue to open a file, and then make the payments, do lab tests and other investigations, then wait again to be attended to. Then there is the pharmacy where they further queue to get their medicines. If they get stuck in one process, they can't continue with the next one. Frequently, they get reappointed even after spending that much time queuing (Clinical officer, KNH).

Notwithstanding the long queues and extended waiting times at public health facilities, private facilities were not always considered superior in providing healthcare services. Some of the caregivers opined that the services offered by private hospitals were not always commensurate with the fees that they charged. In addition, the public hospitals were viewed to have medical experts and specialists, who enhanced the quality of healthcare provided at the public facilities.

The focus group discussants at MCRH stated it in this manner:

In public hospitals, you find specialists who are capable of treating any kind of serious illnesses or conditions. They are well qualified and they know their work so they give us confidence. It is not always the case at the private health facilities. Some of the private hospitals do not have qualified doctors; you can easily find quacks over there (FDG, MCRH).

5.5.5 Satisfaction with attitudes of health workers

The perception on attitudes of health workers is considered to be another important indicator of satisfaction with the health services offered at a given health facility and, according to the respondents in this study, the attitude of the health workers was more favourable at the private dental clinics than at the public oral health facilities. At the private dental clinics, the attitude of the health workers was described as very good by 56% of the respondents, good by 32% and average and below by 12% of the respondents who attended these clinics, while those who attended government facilities gave respective ratings of 22%, 40% and 38%, for public oral health facilities (Figure 5.5). There was a clear statement from the focus group discussants that health workers in public facilities were not caring enough, and they did not interact sufficiently with patients. The study participants expressed some empathy with the large workload that the health workers at public health facilities had to endure, arising from the large numbers of patients that attended these institutions *viv a vis* those of the private sector; and this, they opined, may affect the health workers' attitude towards work. This is how participants in one focus group discussion stated it:

The health workers at public health facilities have a rather uncaring attitude compared to the private dental clinics. They don't give us enough time; instead, they shout at us and sometimes they accuse us, unlike in the private clinics where they are polite and they handle us well. But we can see that they are overworked with the number of patients and that can be very tiring (FGD, MCRH).

The researcher observed very good rapport and camaraderie between caregivers and health workers at GCH, more than the other two hospitals. Nonetheless, the environment at all the HIV-care facilities was very cordial and the patients attending these clinics are treated with courtesy

and sensitivity. In the focus groups at GCH, the participants, unsurprisingly, had this to say about their health workers at the HIV-clinic:

The health workers here give us respect and they care well for us, even when we have social problems. When we ask questions, we get the answers accordingly and there is no discrimination. The doctor, nurses and counsellors are all very friendly. We really appreciate the services we receive here (FGD, GCH).

5.6 Expectations on oral healthcare delivery

During the focus group discussions, the caregivers indicated several ways which they considered pertinent in improving the utilization of oral healthcare particularly for their children in the NCC. For example, there was a strong desire to have government-run dental clinics brought closer to them for easier and more convenient access to regulated oral healthcare services. The participants in the focus group discussion at KNH were of the opinion that there were very few dentists and the dental clinics were located very far from where they resided, so they were forced to seek oral health services from private dental clinics. This is how they stated it:

The dental clinics in the county government are located very far from where most of us live. 'Kule mashinani hakuna mahospitali ya meno ya serikali' (there are no government dental clinics at the grassroots). Many times we go to the county health centres and we don't find a dentist, and our children have to go to school. We are told that they only come once or twice a week (FGD, KNH).

There was also a call for more government subsidy for oral healthcare services, and an increase in the number of dental officers at public health facilities. This is how participants in one of the focus group discussions put it:

At the same time, the government should make the cost of oral healthcare more affordable because many children have issues with their teeth but we cannot afford to take them for treatment. If we go to public hospitals, there are so many patients there who are seeking care but there are very few dentists to attend to them and the cost is still high (FGD, MCRH).

It was also suggested that multiple forums could be used to disseminate oral health education and information on oral healthcare services to consumers in a civic manner, similar to other health issues that they encountered. The participants in one focus group discussion at GCH affirmed this sentiment in the following statement:

When it comes to HIV and TB outbreaks, or even vaccinations for children, there are door-to-door campaigns and follow-ups by community health workers. Some of them volunteer their services for free. They can also integrate oral health in their campaigns and do a follow-up on that as well (FGD, GCH).

One of the KI at KNH was of the view that oral health education is not given the same priority as other illnesses of public health interest, thus disenfranchising patients from taking charge of their own oral health. He stated it this way:

Patients have a lot of information on other health issues of public health importance, except oral health. I can have a good discussion with caregivers here on issues like family planning, diabetes, and hypertension. They have the knowledge because these health issues are discussed in the media and at public campaigns. When it comes to oral health, there is very little public information (Clinical officer, KNH).

He further stated that there was also poor participation by dentists and other oral health providers in creating awareness and sensitization on oral healthcare. For example, there were hardly any formal services provided by dentists for PLWHA at the HIV-clinics, even by way of consultation and advice. This is what he said:

It is an issue of sensitization on oral healthcare. We require the input of the dentists and other oral health providers. At the KNH HIV-clinic, we have integrated other specialized clinics, for example, we have regular days when the dermatologist comes to see patients. But we have no dental consultations so the patients are not sensitized about oral healthcare (Clinical officer, KNH).

Additionally, he stated, the protocol of patient review at HIV-clinics did not provide for much on oral healthcare. “*We don’t spend much time on clinical examination of the mouth and the teeth.*”

We just check to see if patients have candidiasis on the tongue. Besides that, even if the patients have dental caries but do not complain of pain, we don't pay much attention. Moreover, the software that we use to review patients has a very small component of oral health examination (Clinical officer, KNH).

In summary, the findings reported in this chapter indicate that children with HIV/AIDS in NCC consume oral healthcare very poorly in terms of proportion, rate, and the timeliness with which they utilize dental services. The pattern of oral healthcare utilization indicates that children visit the dentist only for pain relief, with no reports of visits for preventive care and/or early intervention of disease. The children do not have a usual source of oral healthcare and frequently, there is delay in seeking treatment for the child, sometimes extending to between five and six days after the onset of pain. The foremost constraint to utilizing oral healthcare is perceived high user-cost of oral healthcare, which is further compounded by the out-of-pocket mode of payment for health services. Having health insurance is militated against by irregular incomes arising from informal employment and low-income earnings, and additionally, the caregivers have poor enrollment with the social health insurance mainly because of misinformation on operations of the NHIF. The structural factors that influence caregivers' choice of oral health provider include distance to the service location, cost of healthcare services and the operating hours at the oral health facility. The caregivers choose cheap, nearby oral health providers where they walk or use quick public means of transport, thus reducing transport costs and the inconveniences of lengthy travelling distances. There is clear preference for utilizing private oral health providers because of perceived better organization and speedy delivery of services at these health facilities. Whilst cleanliness is acceptable at both categories of health facilities, the challenges encountered at public institutions are long queues, extensive waiting times and uncaring attitudes of health workers.

CHAPTER SIX

VOICES OF THE CAREGIVERS

6.1 Introduction

This chapter presents the narratives of female caregivers of children with HIV/AIDS who were purposively selected for reasons aligned to the objectives of the study. The caregivers narrate their lived experience with HIV/AIDS, as being either infected or affected by the condition. The stories presented by the six women are distinctly varied, giving different perspectives of the challenges the caregivers face in accessing oral healthcare, and thereby, providing additional information to the phenomenon of study. The narratives are important in complementing and giving further shape and depth to the findings of the survey. They 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.

6.2 Case narratives

6.2.1 Caregiver of low socio-economic status whose son (and herself) suffers from dental caries and toothache. Her biggest constraint in utilizing oral healthcare is affordability of dental services, which is compounded by lack of health insurance.

This story depicts the general life-circumstances of most caregivers in the study and illustrates their circumstances of endemic poverty and challenges faced in accessing oral healthcare for themselves and their children. According to this narrator, 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. The narrator voices a preference to utilizing oral healthcare services at private health facilities because of the perception that these institutions offer better quality of care.

However, due to financial constraints, she is planning to seek dental care services for herself and her child at a nearby public general hospital. The narrative:

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, which usually 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 sicknesses that I was suffering from. When I was told that he also has the virus, I was devastated and really cried. But he is not sickly himself, so he is not yet using ARV medication. 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 normally 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 and spoke to 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 in the clinic is free and we are very happy about that. I would prefer to attend private health facilities. 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 waiver some charges, 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).

6.2.2: This narrator embodies the perception among most caregivers that having rotten, discoloured teeth affects self-esteem and social decorum, even at the work place. She demonstrates resolve in having replacement for her decayed teeth which were previously extracted, against the odds of her livelihood circumstances.

Her story illustrates the value that many caregivers like herself, place on the outward show of teeth. Good oral health among the caregivers is perceived in terms of aesthetics and appearance of the teeth, rather than the absence of dental caries and other oral diseases. Since social interaction is a daily occurrence for most of these women who are mainly business people, traders and workers, the focal point of their entire mouth appears to be the appearance of the teeth, perceiving white teeth to denote cleanliness. This is her narrative:

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. I am in a discordant relationship with my husband, 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 even tell that I have the condition. It has now been eight years because that is the age of my last-born. I have two daughters and only the second one is infected, maybe because of breastfeeding. She does not know it herself, although she is 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 also 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. The teeth were paining on and off, but 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 talked to customers I had 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 prices 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).

6.2.3: 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 has not given priority to oral healthcare for her nephew whom she adopted following the demise of her sister from HIV/AIDS.

The narrator is a woman with tertiary level of education and moderate means of living. Her story is presented on account of being affected by HIV/AIDS through caring for a nephew who suffers from the affliction. At first, 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 admits to not having paid much attention to his dental needs because of lack of dental awareness and the need to utilize oral healthcare. This *inadequacy* in OHL was a common finding with most of the caregivers, together with their healthcare providers at the HIV-care facilities. The narrative:

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. At that time, the boy was only eleven months old; he is 10 years old now. He began taking his ARV medication when he was four years old, and I bring him to the HIV-clinic here for review and follow-up once every three-four months. Some of the challenges I face being the caregiver of Isaac is finances to meet his dietary requirements. 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. It is not such an easy job. 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 the discolouration, 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 unless there is pain. There was a time that my older daughter had a toothache, but she later had the tooth extracted and she is now okay. She went to a nearby clinic which was convenient because I just sent her there on her own. I, myself have never been to the dentist and, as you can see, my teeth are very okay; they are white and I have no 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 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; for example, I have a doctor who always does a follow-up whenever I have any medical issue. 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. That always annoys me so much (42 -year-old caregiver, GCH).

6.2.4: A grandmother who is a caregiver to her grandchild with 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 which she had 'successfully' used for her own children.

Grandmothers in this study symbolize an identifiable category of guardians of children with HIV/AIDS. Despite being of older age, they sometimes find themselves thrust into the precarious position of 'parenting' grandchildren who are orphaned through the ravages of HIV/AIDS. As depicted by this narrator, older caregivers are more inclined to use alternative remedies linked to age-old traditions that they have used in the past, rather than rely completely on 'formal' oral healthcare. The narrative:

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 had 'this' illness, but I didn't know how to approach it. I am not sure if she suspected it herself. In 2014 when she got her first pregnancy, 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 that 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 now 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, 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.

I have little information about dental illnesses and I have not suffered much from dental problems myself but what I know is that when teeth are erupting, children suffer from fever and diarrhoea. That is a true fact, because I saw it with my own children. With my grandchild, I brought her here to the clinic, but the doctor told me that teething cannot cause diarrhoea, and perhaps she 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 their gums with a powder from 'home' which relieved the discomfort of teething and reduced the diarrhoea. I did the same with my grandchild and she is now okay. I also know of other teeth which develop early and make the child extremely ill, but fortunately my granddaughter does not have that problem or I would have taken her home to have them removed. My granddaughter has not started brushing

her teeth, but I will teach her when she starts going to school. If a child brushes their teeth too early, they can destroy their milk teeth which are very delicate. A person does not need to go to the dentist unless they have pain, or a problem with their teeth. Sometimes they 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. 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. For my granddaughter's condition, I get free treatment here at the HIV-care clinic, but for her other medical expenses my older children have to help because they are working, although their jobs are not very well-paying (65-year-old caregiver, KNH).

6.2.5: A woman with HIV/AIDS who suffers from dental caries and cancer of the oral cavity. As per her socioeconomic circumstances, she is unable to afford oral healthcare or treatment for her cancer. Largely, she depends on charitable organizations and well wishers for her up-keep and medical expenses. Her 2-year-old son is also infected with HIV/AIDS.

The narrator presents her experience with having chronic dental pain and other oral manifestations of HIV/AIDS which led to cancer of the oral cavity. She was unable to access timely treatment for her life-threatening illness, and she is frequently sickly and cannot do much to improve her living conditions. Her story embodies almost all the individual and structural barriers that women of her socioeconomic status face in the utilization of oral healthcare. According to her narration, the biggest challenges to accessing oral healthcare are having money to pay for services when one has no health insurance and the high cost of healthcare. She was

recently referred for specialized treatment at the highest level of the healthcare system but that only gave her additional challenges of long travel distance to the referral hospital for which she perpetually lacked transport. At the hospital she encountered a long list of patients seeking similar specialized oral healthcare. The health workers at the HIV-care clinic where she is enrolled come to her rescue several times in different ways and their caring attitude gives her solace. She gets additional financial assistance from other charitable organizations. This is her narrative:

I knew of my HIV-positive status about 8 years ago, when my new-born son started ailing and suffering from various sicknesses repeatedly. By the time he was one-year-old, he only weighed 3 kgs. I think my neighbours must have suspected my condition because they advised me to bring my child here to the HIV-clinic at Getrudes Hospital. This is where he was discovered to be HIV-positive. He was then admitted and started on treatment. Unfortunately my older son who is 10 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 my children and me 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 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 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. I did not have transport because I live in Gachie and Kenyatta hospital is very far, but the social worker gave me some money for fare. At Kenyatta, I was given a date to go back for a 'biopsy' of the swelling on my tongue. I was also supposed to get some medicines but they were not available in Kenyatta, so I came back and I was lucky to find some of the medicines here at the HIV-clinic. I did not get extraction of my painful tooth because I didn't have the money to pay for it. I went back to the hospital later for my results and was told that I have cancer of the mouth. Then surgery was done to remove the swelling, and I was then told that I needed chemotherapy and radiotherapy. Everything was just happening to me very fast. I have not yet done the chemotherapy and radiotherapy because of several reasons. Firstly, is that 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 Kenyatta, 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, but 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 Kenyatta 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 stay 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 there, we are happy because they encourage us on how 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 even 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 live properly, leave alone getting treatment when we are sick (37-year-old caregiver, GCH).

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

The narrator talks about her challenges as 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. She found herself thrust into the caregiver role when her grandchild was abandoned in her care, and, despite her advanced age of 71 years, she has had to leave her rural home and relocate back to Nairobi to seek advanced treatment for her grandchild at Kenyatta National Hospital. To sustain herself and grandchild, she undertakes menial jobs, occasionally supplemented by resources from the child's older cousin who shares guardianship with her. She

did not seek oral healthcare when her granddaughter first suffered from swelling of the jaws and the oral cavity, partly due to ignorance and partly because of lack of access to oral health providers at her rural home. She has also been accused of poor management of her granddaughter's HIV/AIDS condition. This is her narrative:

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 why 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 Hospital 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? So I decided to relocate from home which is Homa Bay and come to Nairobi so that my grand-daughter could get treatment, but even that has taken a long time. Imagine, I have been in Nairobi since November last year (i.e. 2015), and she only started chemotherapy in March this year (i.e. 2016)! It is very depressing; this child has suffered so

much. She has spent 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 to relocate to Nairobi from Homa Bay, 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 to give her the HIV medicines which I get from the clinic every single day; the doctors here say 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. The doctors 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).

The lived-accounts of the caregivers support other findings of the study that financial constraints and lack of information on oral health are constraining factors in the utilization of oral healthcare among caregivers of children with HIV/AIDS. Although the circumstances of the women were very different, caregivers of children with HIV/AIDS face common challenges when it comes to the utilization of oral healthcare. Almost all the narratives depict the weak economic position of

the women which obviously impacts the timely utilization of oral healthcare for their children. The children frequently put up with oral pain while the caregivers self-medicate because they lack ready cash and/or health insurance to access oral healthcare. Unfortunately, the delay in obtaining treatment when it is needed only complicates dental illness, making it more difficult and expensive to manage as illustrated in narratives 6.2.5 and 6.2.6. Poor oral health literacy also creates a barrier to oral healthcare utilization among the caregivers; an example is case narrative 6.2.3 where a woman of good education, moderate means and access to health insurance is not cognizant of the need to utilize oral healthcare services for the child under her care. Additionally, caregivers have little information on the co-morbidity of HIV/AIDS with oral manifestations and are unable to make the connection between the illnesses in the oral cavity with the medical condition that they have. As one narrator (grandmother) in 6.2.6 stated, *'how can having HIV/AIDS cause you to have cancer of the mouth?'*

This chapter also identifies grandmothers as a striking category of caregivers of children with HIV/AIDS, making up two-thirds of the case narratives. According to their narratives, they were forced to step in and raise orphans who were left behind as a result of sickness and death, and abandonment, 6.2.4 and 6.2.6, respectively. It was apparent that the grandmothers in the narratives made enormous sacrifices, against all odds, to care for their grandchildren, but the financial strain sometimes proved to be too much for them. In addition, they faced challenges in meeting the children's needs in the context of a disease they appear to know very little about, such as strict adherence to time in dispensing ARV medication. In narration 6.2.6, there was physical and emotional strain from an elderly caregiver in having to interrupt her normal rural life and relocate to a new environment to begin a different kind of life. As depicted in these

narratives, the older caregivers are also more likely to rely on traditional and self-care health practices which ultimately lead to a delay in seeking biomedical healthcare.

The narratives clearly underscore the influence of structural factors in determining choice of oral health provider. Narrator 6.2.1 stated a preference for private oral healthcare which she perceived had better organization and service delivery; however, the high cost of care at the private health facilities sometimes deterred her from utilizing these facilities. Narrators 6.2.5 and 6.2.6 who were referred for specialized care to the highest-level hospitals allude to challenges of finding long waiting lists at the recommended institutions. In addition, narrative 6.2.6 sheds some light on the impact of rural-urban structural factors in accessing oral healthcare. This narrative suggests that rural communities experience geographic isolation in oral healthcare with probable fewer oral health professionals and facilities and, with the challenges of higher rates of poverty and a large elderly population, they are unlikely to purchase health insurance to assist in facilitating access to oral healthcare.

CHAPTER SEVEN

DISCUSSION

7.1 Introduction

This chapter discusses the study findings on determinants of the utilization of oral healthcare for children with HIV/AIDS among female caregivers in NCC. The discussion follows a thematic sequence based on the specific study objectives, which are linked to the assumptions and the theory that guided the study.

7.2 The discussion

The study employed a mixed method research design with integration of both quantitative and qualitative results, which allowed the researcher to have more in-depth information and knowledge of the respondents' experiences, as well as provide rich data sets. The information garnered from the study is limited to a cohort of female caregivers of children with HIV/AIDS in NCC and, therefore, generalization of the results presented should be done with caution.

Individuals and populations differ in how they define an oral health problem, determine its seriousness and decide whether or not to seek care. The first objective of the study, therefore, was to examine the caregivers' perceptions of oral health and culture and its influence on the utilization of oral healthcare for children with HIV/AIDS. According to Kleinman's theory of explanatory models (Kleinman, 1980:106), individuals and groups can have vastly different notions of health and disease, thus, in one cultural setting, a painful tooth may be enough to motivate care-seeking while in another, bleeding, swelling or fever may be necessary before care is sought. Similarly, decisions about whether to comply with a suggested treatment regimen or engage in self-care are

heavily reliant on cultural influence. The findings of this study unearthed accounts of culturally-based beliefs and practices among the caregivers of children with HIV/AIDS, which influenced (and oftentimes hampered) the utilization of oral formal healthcare for their children. Being an urbanized population, the respondents' perceptions and cultural beliefs were sometimes shaped by modern scientific knowledge mixed with traditional African myths and theories of oral diseases and oral health.

That perceptions is a measure of the severity of illness is played out among the caregivers in the study, in that, they perceive 'good' oral health based on the aesthetic appearance of the dentition, and on 'looking nice' rather than on the absence of disease and loss of function. To the caregivers, what constitutes good oral health is having teeth that are white and/or having teeth that are arranged in a good line; in other words, white evenly placed teeth are akin to having good oral health. On the other hand, there is much lower value placed on descriptions that depict the absence of disease such as rotten teeth, painless teeth and the absence of bleeding and swelling. Participants in the focus discussions frequently expressed a desire to have clean white teeth for themselves and their children, and/or evenly arranged teeth which had no gaps in-between. Seemingly, the caregivers embrace their self-worth in having aesthetically pleasing teeth that enable them to interact more confidently with others and contribute to social respectability and decorum.

The findings of this study, however, are equivocal on how individual caregivers perceive the oral health status of their children. This is because nearly equal proportions of caregivers described their children's oral health status as 'good', 'poor' and/or average. These descriptions, once again, were solely based on the aesthetic appearance of the child's teeth rather than their dental illness.

Given the high value that caregivers placed on the outward show of teeth, any negative consequences attached to poor oral health or negative outcomes were likely to be related mostly to appearance and social acceptability. In literature, self-perceptions of oral health form the focus of several studies and have been reported as important constructs in influencing oral health decisions and healthcare utilization patterns. For example, a key population-based study in Brazil observed that individuals who rated their oral health as ‘good’ had higher utilization of dental healthcare than those who rated theirs otherwise (Araujo *et al.*, 2009: 1067) whereas, caregivers’ fatalistic attitudes towards children’s oral health were significantly associated with poorer perception of their children’s oral health and utilization of oral healthcare. In one American study, caregivers with poor perception of oral health were seen as *less* likely to brush their children’s teeth and/or seek dental care (Sohn *et al.*, 2008:485), which may have been the case among the caregivers in the current study.

According to the study findings, the caregivers do not view decayed teeth as an illness which necessitates seeking oral healthcare but, instead, they envision discolourations on teeth as having arisen from the chronic use of ARV medication. To the caregivers, it is quite normal for children with HIV/AIDS to have ‘blackish teeth’, in fact, most of the children who visited the HIV-care clinics did not appreciably differ from each other in dental appearance. This conviction was relayed amongst themselves over time until it became completely believable. The handling of health information where people discuss their symptoms with others before they discuss them with the doctor recounts the phenomenon of the lay referral network described by medical social workers. For instance, Campbell and Roland (1996: 75) noted that many people with certain illnesses did not usually consult their doctor and, further, consultation patterns were influenced by a range of social and psychological factors. People think and explain to themselves in their own

way-which they share with others- the misfortunes that happen to them, the ailments which affect their bodies, and the disorders that enter their lives Heller *et al.* (2005). Their ideas are taken as logical and valid in their own right even though they may not be consistent with medical science or any other healing system. These lay explanations go beyond commonsense in that explanations beyond the immediately obvious are included. In this study, such conversations served to lessen the fear associated with the threat of disease (dental caries) and were central to the caregiver's decision not to seek professional advice or utilize biomedical oral healthcare for the treatment of dental caries in their children. O'Donnell (2007:2826) alluded to this from a different perspective, stating; where a group of people banded together is in poor health this becomes the norm and illness may not be easily recognized. Further, if treatment coverage is low, there is less opportunity to learn of its benefit and the unfortunate outcome can be continued tolerance of illness and disease.

From the study findings it was clear that caregivers largely subscribe to attitudes that diminish the value of the first teeth in children. They consider these to be temporary teeth which will remain in the mouth for only a short period; therefore, they are not as important as the permanent teeth. At the same time, loss of permanent teeth is accepted as the natural progression of the dentition in old age which may not be reversed or altered. Such kinds of perceptions among the caregivers result in low priority for the use of oral healthcare, particularly for young children. Whilst these findings are not unique and they have been reported elsewhere (Hilton *et al.*, 2007: 432; Wong *et al.*, 2005: 507; Horton and Barker, 2008: 24; Kwan and Holmes 1999: 456), they shape the culture of utilizing oral healthcare among the caregivers in the study which is casual and problem-oriented, mainly, to rid of the offending tooth. The resulting evidence is that utilization of dental care for the younger children is very poor, whilst for the caregivers the treatment preference is

merely for tooth extraction. It is also possible that this pattern of oral healthcare utilization is strongly influenced by the income level and other socio-demographic factors pursuant to the caregivers, which are discussed later in this chapter.

Literature is rife with reports of deleterious cultures and practices on infant-feeding which involve putting the child to bed with a bottle of sweetened liquid, or giving the child a pacifier dipped in honey, and/or sharing eating utensils among siblings and caregivers (Woolfolk *et al.*, 1985; 141; Weinstein *et al.*, 1992:377; Ramos-Gomez *et al.*, 1999b:398). Such practices frequently result in nursing-type of decay of the infant's teeth. More recently, Broder *et al.* (2006: 141) reported a rise in bedtime bottle feeding practices whose contents are juice, soda and other sweetened drinks by children of African American fathers. In the current study, there was minimal reported use of the nursing bottle amongst the respondents; instead, infants were almost exclusively breastfed and later weaned on traditional 'African' foods such as *wimbi* porridge and pumpkins and fruits. These are the recommended best-practices in infant feeding for PLWHA to decrease the likelihood of mother-to-child-transmission (MTCT), advice which was given to the caregivers by their health workers. For the benefit of oral health, it served to reduce some of the causative factors of dental caries among the children with HIV/AIDS.

While these weaning practices are commendable, the caregivers nonetheless, have very strong beliefs and taboos relating to cultural myths and folklore on teething processes in infants, among them, the belief that teething is the main cause of high fever and diarrhoea in infants. Many of the discussants firmly believe in a direct link between teething and diarrhoeal diseases in infants. A case in point is the grandmother caregiver (case narrative 6.2.4 on p. 110) who, despite the advice of a medical doctor, resorts to treating these symptoms in her granddaughter using age-old

traditional methods. According to McIntyre and McIntyre (2001: 252) the argument usually leveled against teething as the cause of systemic upset is that infancy, and especially the time of eruption of deciduous incisors (6-12 months), coincides with the diminution of the circulating maternal humoral immunity and establishment of the child's own; therefore, most children at this age are susceptible to a myriad of minor viral infections. A study reported by King *et al.* (1992:83), explored the possibility that certain symptoms such as fever and irritability may result from undiagnosed primary herpetic infection in the children.

There was yet another strongly held myth among the caregivers about what is well-known as 'plastic' or 'nylon' teeth in lay terms. These are pearly white elements that sometimes occur in the pronounced canine tooth bud region of infants. Anecdotal evidence among lay folks suggests that these teeth are infested with worms which have the potential of causing severe illness among children such as excessive or prolonged diarrhoea, difficulty in breathing, or even death. This occurrence, also referred to as 'millet' disease has been reported in several other regions in sub-Saharan Africa (Accorsi *et al.*, 2003:25; Kahabukha *et al.*, 2015:2). According to discussants in the current study, treatment for this condition is found among traditional healers in certain rural locations, who 'extract' the nylon teeth using crude surgical instruments such as razor blades and needles *albeit* in dubious settings. In dental parlance the practice of extracting the canine tooth-bud is adversely referred to as infant oral mutilation (IOM). It has been reported among certain ethnic communities in Kenya and the region (Mutai *et al.*, 2010:96; Davidovich *et al.*, 2013:34). Unfortunately, to any oral health practitioners engaged in the formal healthcare to children, IOM is a worrisome practice for several reasons. Firstly, it inflicts severe pain on the infant and, secondly, seeking care from traditional healers may delay life-saving care for childhood illnesses. Thirdly, the methods used in the traditional treatment could lead to medical complications such as

excessive bleeding, septicaemia, aspiration pneumonia, and/or the risk of blood-borne diseases, for instance, hepatitis and HIV-infection. Finally, there is the risk of exposing the child to enamel defects and/or hypodontia of permanent teeth as a result of destruction of the underlying tooth germs whilst carrying out unorthodox extractions which has been reported by Masiga and Musera (2003:173). The caregivers in the study are, however, seemingly oblivious of any potential risks involved in this practice. The conviction among some of the discussants is so immense that in some instances where the caregivers' spouses do not approve, the women 'secretly' visit the traditional healers on the pretext of going upcountry to spend time with their parents. While high socioeconomic conditions do not favour the occurrence of false teeth; nonetheless, they have no influence on the mode of treatment suggesting that, when certain beliefs are rooted in a population they become more difficult to change thereby, perpetuating the vicious cycle through generations Accorsi *et al.* (2003:28).

Additionally, the caregivers see it as a bad omen when an infant is born with teeth already erupted in the mouth, or when teeth erupt around the birth period of the infant. This event, in biomedical terminology, is known as natal or neonatal teeth and is explained as precocious eruption process and/or superficially placed tooth-germs of the normal first series. Whilst some caregivers quietly look for a dentist to have the tooth/teeth pulled out, the general construct by the discussants is that it necessitates the child to undergo some form of ritual cleansing by select traditional healers normally found in the village. The traditional practitioners are also considered capable of taking on other forms of oral health 'treatment' for young children for instance, excision of elongated uvulas to prevent the child from coughing excessively, and/or nipping ankylosed or 'tied tongues' which the caregivers believe leads to speech delay in young children. In addition, some believe that frequent childbirth results in calcium deficiency and tooth-loss in the mother as a result of losing

calcium to the growing baby and, finally, some of the discussants stated that the ‘wet conditions’ surrounding childbirth resulted in ‘soft teeth’ in children.

The use of traditional medicine commonly arises from the sum total of knowledge, skills and practices based on theories, beliefs and experiences indigenous to a culture. Despite their urban dwelling and the likely overwhelming influence and dependence on modern medicines, many discussants in the current study report the exploitation of traditional and home care remedies. From time to time, they resort to the use of home remedies as first-aid measures to relieve toothache and gum swelling before seeking formal oral healthcare if the problem does persist. The traditional remedies commonly comprise herbs or *mitishamba* which, according to them, are sourced from special practitioners who have the correct knowledge, passed on generationally. Traditional remedies are acceptable to the caregivers because advice on their use comes from sources they trust, such as parents and grandparents; thus, they view them as culturally appropriate and holistic for consumption. Further, they find these methods to be reliable, convenient, cost-effective and without side effects. Some of the caregivers reported the use of cotton balls soaked in aspirin as well, which they use to relieve pain and swelling arising from a toothache, while others habitually clean their teeth with salt and/or charcoal, or they gargle with salty water to maintain good oral hygiene and prevent gum disease. The effect of this reliance on home remedies and/or self-care measures frequently leads to delay in utilizing formal oral healthcare. This finding is consistent with the observations on self-care reported by McGrath (2005: 304).

The prevailing use of traditional methods for homecare practices among the caregivers is not unlike that of many cultures in the African region, for example, Ngilisho et al. (1994:241) reported that dental patients in Tanzania were commonly treated by traditional healers; more than half of

their study population habitually sought oral healthcare from traditional healers who use local herbs to carry out treatment. In this Tanzanian study the pattern of health-seeking was not altered by the establishment of modern emergency oral healthcare services in the region. In the current study, it was further evident that caregivers sometimes resort to the use of traditional methods because of perception of prohibitive costs of formal oral healthcare services, an observation that is similarly reported by other researchers. For example, Nyamongo (2002:337) states 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. Nonetheless, while caregivers in the current study reported the use of traditional remedies for themselves, they tend to use them less for their children, a similar observation to that reported among the Chinese in the United States by Wong *et al.* (2005:508)

The second objective of the study was to establish the effect of socio-economic factors among the caregivers, on the utilization of oral healthcare for children with HIV/AIDS. Socio-economic status (SES) is conceptualized as the societal standing of an individual or group, and is commonly considered as a combination of education, income and occupation. Close examination of the effect of SES in general, often reveals inequalities in access to resources, plus issues related to privilege, power and control that ultimately result in disparities in access to healthcare. The caregivers in this study exhibited middle-low to low socio-economic attributes, characterized by correlates such as low educational levels, low household incomes and residence in high population-density neighbourhoods and informal settlements in NCC. About two-fifths of the respondents in the study have not attained an educational level beyond primary school; accordingly, they are mainly engaged in non-formal employment comprising small trades such as market stalls, hair salons, and

the sale of second-hand clothing and other small household commodities. The largest proportions of the caregivers live on monthly household incomes of KES 0-10,000, against which they balance their household expenditures including healthcare. On face value, these income levels may suggest that the women have access to financial resources; however, taking into consideration the tough conditions of urban dwelling, the caregivers' incomes in most cases, fall drastically short of the recommended minimum wage for urban dwellers in Kenya of between KES 13,592 and 17, 199 (Business Daily, 13th July, 2016). This suggests that the caregivers are most likely facing the common challenges of the economically weak, which commonly includes disparities in access to healthcare. Indeed, woeful living and inability to access financial resources and timely oral healthcare is depicted in most of the lived-accounts of the caregivers in the case narratives.

There were several socio-demographic factors among the caregivers that emerged as pertinent to the utilization of oral healthcare for their children. Even though most of them were living with their spouses in stable marriages, it was evident that female caregivers are the main decision-makers in the families with regard to matters of utilizing healthcare for their children. They voiced a strong opinion and firm belief that mothers make the best decisions on when, how and from where to access healthcare for their children. This finding may be interpreted to mean that these women have some control over household finances which gives them authority to make certain decisions in the home. Rashed *et al.* (1999:1003) suggested that expenditure on treatment is positively correlated with women's income particularly in developing countries. Additionally, there is evidence that the utilization of healthcares increases with the control that a woman exercises over household finances (Beegle *et al.*, 2001:144). It is, therefore, conceivable that the utilization of oral healthcare for children with HIV/AIDS may improve to a great extent if their caregivers were more empowered financially.

In this study, grandmothers are an identifiable category of primary caregivers of children with HIV/AIDS, forming two-fifths of the case narratives. 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-particularly grandmothers- following the loss of biological parents from ravages of the disease. 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: 56). This kinship is illustrated in the case narratives involving grandmothers 6.2.4 and 6.2.6 and an aunt, 6.2.3 (pp. 110, 115,108, respectively). In some extended families, these unforeseen responsibilities strain elderly caregivers who are already weighed down with physical ageing, and financial struggles. Nyambedha *et al.* (2013:308) 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; views which resonate well with those of one key informant in this study who opined that, while extended families embraced the physical, emotional and spiritual needs of orphaned children as well as providing them with food, clothing and shelter, the utilization of oral healthcare was bound to be given a lower priority due to financial constraints. The grandmothers in this study were plunged into these unfortunate situations, causing them to resort to carrying out menial work in order to find additional resources to utilize oral healthcare for their grandchildren.

A pertinent finding of the study is the poor pattern of utilizing oral healthcare by children with HIV/AIDS in terms of the proportion who utilize care, the rate, and the timeliness with which their caregivers seek care. Almost three-quarters (71.1%) of the children who attended the HIV-care clinics during the study period had never visited the dentist nor utilized any form of oral healthcare services. These are worrisome results considering that the national prevalence of non-attendance in

the same age group is much lower, at 46.7% (National Oral Health Survey, 2015:15). In addition, the children visit the dentist for symptomatic reasons only, which was mainly toothache and swellings or ulcers in the mouth. Frequently, there is delay in seeking treatment sometimes extending to between five and six days after the onset of pain. Further, the children do not have a usual source of oral healthcare as 98 % of them are not enrolled with an oral health provider which might enable them access constant dental care; instead, caregivers utilize oral healthcare care for their children in an *ad hoc* and unplanned manner. This pattern of oral healthcare utilization does not tally well with recommended best practices, ‘dental homes’, which embrace the concept of regular, comprehensive, continuously accessible oral healthcare for children in a family-oriented manner (American Academy of Paediatric Dentists, 2015). It is argued that, having a usual source of oral healthcare facilitates increased contact of children with oral healthcare providers; in particular, it provides a locus of entry into the healthcare system when specialized types of care are needed (Lewin-Epstein, 1991:552). Notwithstanding, about two-thirds of the children did utilize care in the period within 12 months of the study, an accomplishment which may be taken to indicate that oral healthcare utilization for the children has gained some footing with time.

According to the study findings, the caregivers perceived the user-cost of oral health services to be very high and oftentimes, this affected the timely utilization of oral healthcare. Slightly over thirty per cent (31.5%) of the caregivers rated the cost of oral healthcare services as *very expensive*, 46% rated the services as *expensive*, whilst only 17.5% of the respondents rated them as *affordable*. They argue that the user-cost of oral healthcare services is *unaffordable* against their take-home income and, going by this, they either identify other alternatives or they avoid using the services altogether. It is realistic to speculate that some form of health insurance would have a mediating effect on the socioeconomic variables among the caregivers and improve access to regular use of

needed oral health services for their children. However, it is also arguable that taking up health insurance is largely tied to having a regular source of income. Accordingly, the study findings show that more than two-thirds (68%) of the caregivers did not have any form of health insurance. Most (75%) of the respondents who accessed oral healthcare for their children paid for the services from out-of-pocket (OOP) expenditure. It was also apparent from the focus group discussions that caregivers grapple with balancing household expenditures to ensure that all aspects of their children's livelihoods are met, including healthcare. This sort of dilemma was highlighted by Ha *et al.* (2002:69) who observed that expenditure on healthcare in Vietnam could at times account for up to 80% of total household per annum, thus exerting unplanned financial burden on individual families. For the low-income earners as the caregivers in the current study, such costs are likely to determine preferential allocation of household resources to other consumable goods at the expense of any non-urgent oral health problems; hence, the children (and their caregivers) would mostly only attend for treatment when pain from toothache became unbearable.

Several studies report that health insurance is one of the most important predictors of healthcare utilization; those with dental insurance were found to be less likely to report unmet needs and delayed visits for oral healthcare (Yu *et al.*, 2002:73; Kenny *et al.*, 2005:1364). The insurance effect, according to Bhattia *et al.* (2007:57) appears to operate through a reduction in price paid at the point of service, not a decision by those with high anticipatory need for dental care to selectively purchase insurance. It may be extrapolated from the study findings that lack of health insurance by the caregivers, combined with high OOP spending for health services imposed limitations on regular consumption of oral healthcare. It behooves some action by the national government of the day, to level the playing field in providing universal access to oral healthcare services. This implies protection against the risk that if expensive (relative to an individual's or

family's means) healthcare services are needed, services of adequate quality will be physically accessible, and these services will not prevent persons from using them or impoverish their families

There are essentially two main options for achieving universal health coverage by any government. One is a health system whereby general tax revenue is the main source of financing health services and the other is a social health insurance (SHI) that, in principle, invokes compulsory membership for all population groups. The third alternative of private insurance may play a supplementary role. At independence in 1963, Kenya had a predominantly tax-funded health system but, gradually, a series of health-financing policy changes were introduced. The most significant was the proposal for social health insurance in 1989, the purpose of which was to ensure access to healthcare for all Kenyans and also reduce dependence on out-of-pocket healthcare expenditure for households (Carrin et al., 2007:131). These efforts culminated in establishment of the National Hospital Insurance Fund (NHIF) as the primary provider of social health insurance in Kenya, with the mandate to facilitate access to quality and affordable healthcare for all Kenyans. The membership of NHIF is compulsory for all salaried employees whose premium payments are calculated on a graduated scale based on income, and deducted automatically from the payroll. For the self-employed and others in the informal sector membership is contributory (voluntary), and available at a fixed premium which, in this case, was recently revised to a monthly fee of KES 500. A recent report on the status of the NHIF insurance fund (USAID, 2014) states that the overall national health coverage currently stands at 4.5 million people, that is, 11% of the Kenyan population. However, the report also notes that, whilst coverage is high for the formal sector (98%), that of the informal sector which accounts for about 80% of the Kenyan workforce has proven to be more challenging, and remains at only 16%.

In this study, health insurance coverage with NHIF among the respondents stood at a paltry 18%. The caregivers appear to be largely *uninformed* about the operations of the social insurance scheme which, in their perception, only seemed to benefit those workers in the civil service. Additionally, they are unsure about their capability in keeping up with regular monthly premiums because of irregularity in their take-home earnings and low proceeds. Some of the discussants further stated that, in their experience, the scheme did not offer sufficient coverage for specialized treatments such as X-rays, cancer treatments and dental healthcare; typically in most countries, insurance schemes offer limited subsidy for dental services. Moreover, there is the problem of finding dentists and/or other oral healthcare providers who are willing to offer treatment on the NHIF cover. These views resound with those reported by Egesah (2015: 5) who opined that, whilst people in the informal sector in Kenya are aware of the value and importance of participating in the NHIF scheme to access quality healthcare they are dissatisfied with the service, as a result of the rigid scheme design, dearth of user information about the benefits, and enrollment bureaucracy. For these reasons, the caregivers are deprived of safety nets to cushion them against the high costs of consuming quality oral healthcare.

Another less obvious but possible explanation for poor utilization of oral healthcare among the caregivers borders on psychosocial dimensions. On the one hand they receive free health services at the HIV-care clinics, while on the other hand they are expected to pay for oral healthcare services obtained elsewhere. The caregivers, therefore, play out the ‘Entitlement syndrome’, or deservedness to certain privileges in healthcare. The current position is that all PLWHA receive, *free of charge*, a wide range of high quality medical services *inter alia*, HIV screening and counselling, medical care for opportunistic infections, ARV medication, treatment for sexually transmitted diseases (STDs) and tuberculosis (TB), and psycho-social support. These functions,

according to a clinical officer at KNH, are sustained by national government domestic spending and donor funding through bilateral and multilateral channels such as the United States President's Emergency Plan for AIDS Relief (PEPFAR). In contrast, there are no concessions within these structures, for the provision of free oral healthcare services. When individuals do not get what they feel they are entitled to or deserve, they deem the situation unjust and they may get angry and seek redress. Thus, health workers reported that caregivers frequently complain about the unavailability of dental services and other forms of specialized healthcares at the HIV-care clinics. They noted that, whenever laboratory tests and medicines are prescribed from other hospitals, many caregivers would come back and try to obtain them for free at the HIV-care clinics, even among those who might be able to afford them elsewhere. In true sense, oral healthcare should be a critical component of *comprehensive care* for patients with HIV/AIDS, but for policy makers and payers, a chasm appears to have divided them and, as a result, the oral healthcare field remains separated from general healthcare in the medical care of PLWHA. The most challenging aspects of an 'unalienable right' healthcare system reside in the definition of the basic services to be provided and the mechanisms for financing these provisions. It is clear that basic oral health services as a societal right or entitlement, has neither been defined nor budgeted for in provision of comprehensive care for PLWHA, and this negatively affects the utilization of oral healthcare for children with HIV/AIDS.

The perceptions on health do not only depend on one's sensitivity to signs and symptoms of disease, but may also be influenced by one's health knowledge. Oral health literacy (OHL) thus, is defined as the degree to which individuals have the capacity to obtain, process and understand basic oral health information in order to make appropriate oral health decisions. The study findings indicate that caregivers are grossly deficient on early interventional methods that might help to

mitigate the adverse effects of dental caries among the children; certain domains that negatively impacted on the quality of life and well-being of the children were largely ignored by the respondents. Excluding pain and gum swelling, 25% of the children were reported to be unable to eat certain kinds of food as a result of poor dental health, while 24% of the children had taken time off school because of dental problems; nonetheless, the respondents only sought dental services for painful conditions. Vann *et al.* (2010:1399) examined the impact of OHL among female caregivers in northern Carolina, United States, and reported a positive link between caregivers' low level of oral literacy and poorer child oral-health quality of life, poorer oral health outcomes and detrimental oral health-related behaviours. Given the co-morbidity of oral diseases with the HIV-condition, caregivers of children with HIV/AIDS would draw great benefit from intensification of oral health education and preventive measures. Identifying professional preventive dental care is among activities that fall within normative caregiver responsibilities (Kelly, 2005:1350). When oral healthcare is not instituted in a timely manner due to lack of oral health knowledge, among other factors, children with HIV/AIDS could suffer far-reaching consequences, as illustrated in case narratives 6.2.5 and 6.2.6 (pp. 112 and 115, respectively). With the assumption that education, income and health have a positive relationship with the utilization of modern healthcare, people with higher educational attainment stand to benefit better in income generation and, invariably, can afford better quality healthcare. Some of the mediating beliefs associated with higher education levels are the associations of oral health with overall health. Health workers too, with good oral health knowledge and self-preventive practices play a better role in maintaining optimal oral health for the children under their care. The health workers entrusted with the medical care of children with HIV/AIDS showed lack of command of knowledge on oral health and prevention of dental illnesses, making them ineffectual in presenting the requisite oral health

information to their patients in clear and successful approach. Therefore, caregivers of children with HIV/AIDS are unlikely to get the motivation to utilize oral healthcare for themselves and their children from their health workers. In the opinion of one key informant, this is likely due to not having any form of integration with oral health professionals within the structure of comprehensive healthcare for PLWHA attending the HIV-care clinics.

The study also reports that the caregivers heavily rely on personal social networks, which form their social support framework in utilizing oral healthcare. About one-third of the respondents reported that they frequently sought information from their social networks to assist them in selecting appropriate oral health providers and, this greatly influenced their oral healthcare utilization pattern. The information on health matters is relayed through word-of-mouth consultations and/or telecommunication through the mobile network system. Some of the discussants opined that sometimes, they delay in visiting the dentist because of a previous bad experience during tooth extraction, hence the reason why they look up their social networks to get recommendation on dentists who would extract teeth ‘without pain’. It is generally considered in social norms that religion, which is characterized by institutional practices and beliefs, might have an influence on healthcare beliefs and practices and, therefore, healthcare utilization may differ by religious involvement or religious denominations. In the current study, caregivers’ spiritual practices and religious participation did not influence their oral health beliefs and/or practices in utilizing oral healthcare.

It was evident, on the other hand, that the caregivers perceive HIV/AIDS-associated stigma in being identified as ‘victims’ of HIV-infection. This psychosocial factor resulted in caregivers forgoing oral healthcare for their children in some instances. Additionally, more than half of the

respondents (55%) reported they would not disclose the HIV-status of themselves and/or their children to their oral healthcare providers because in doing so, they perceived prejudiced care. Weiss and Ramakrishna (2006:536) define stigma as a social process that is characterized by exclusion, rejection, blame and devaluation resulting from experience or reasonable anticipation of adverse social judgment about a person or group identified with that particular health condition. These findings resonate very well with those of Sayles *et al.* (2007:814) who reported that, early negative experiences with the healthcare system may result in delaying or forgoing other medical care for PLWHA. The stigma also discouraged the caregivers from disclosing their HIV-positive status to close family members and friends. However, at the HIV-care clinics, the caregivers appeared secure enough to open up about their medical condition.

Patient satisfaction with the non-medical aspects of care is often associated with better compliance with treatment instructions, prompt seeking of healthcare and a better understanding and retention of medical information (Murphy-Cullen and Larsen, 1984:163). The third objective of this study, therefore, was to determine the significance of structural factors in the utilization of oral healthcare among caregivers of children with HIV/AIDS, with reference to characteristics of the healthcare system and caregivers' satisfaction with quality of oral healthcare. Bleich *et al.* (2009: 271) opined that, consumer satisfaction is increasingly playing an important role in the quality of care reforms and health-care delivery, thus, client satisfaction is today viewed as a key component of the health system's response and, the greater the responsiveness of the healthcare system to the expectations of an individual, the higher will be the level of welfare achieved. As a healthcare system's goal, responsiveness has its own intrinsic value (de Silva, 2009:2), for example, a clean hospital environment and pleasant healthcare workers who treat patients with respect may contribute to improving a person's quality of life. While the structural quality of the healthcare system relates to

dimensions such as continuity of care, costs, accessibility and accommodation, patient satisfaction represents a complex mixture of perceived need, expectations and experience. In current philosophy, the user of the healthcare system is portrayed as a consumer, where greater responsiveness of the healthcare system is perceived as a means of attracting consumers.

The healthcare system framework in Kenya has a blend of private and public healthcare providers whose classification is commonly based on the agency that owns the health facility. In the public sector, healthcare providers are under the two tiers of government, national (tertiary hospitals), and local county facilities, while the private sector health providers are broadly classified as faith-based organizations (FBOs), non-governmental organizations (NGOs) and donor, or independently-owned health facilities. It was pertinent for this study to identify the oral health providers that caregivers go to when they require oral health services, and the reasons why they make these choices. It was evident that the highest percentage (57.1%) of the caregivers utilizes oral healthcare services from independently-owned, *albeit* small private dental clinics, 19.5% from public health providers, and 15% from FBOs. The choice of health provider in most instances is based on perception of 'fair' user costs, proximity of the provider to the caregiver's home, and recommendations on quality of services through social support networks.

The geographical challenges of accessibility to health facilities frequently cause patients to use different modes of transport to access formal healthcare, whereas close proximity of the health provider is beneficial in cutting down the cost of transport and the inconveniences of modes of travelling long distances. According to the study findings, the modal range of distance travelled by the caregivers to their oral health providers was 1-5 km, while the range of distance covered was 1-15 km, with a very small percentage travelling more than 15km. The convenience of

proximal service location provides the caregivers with ease of accessibility and this influenced their choice to visit nearby privately-owned oral health facilities. The respondents mainly walked or used quick public means of transport to the oral healthcare facilities of their choice and only in very few cases did they use private means of travel. In many areas, the distance to the health facilities and poor conditions of roads means that time, effort and costs required to arrive at the point of delivery can be substantial (O'Donnell, 2007: 2826). Hausmann-Muela *et al.* (2003:19) further state that limited access to transportation and costly public transport are among challenges facing women while seeking healthcare.

However, it was interesting to observe that, whilst the respondents were unwilling to travel long distances to access oral healthcare, they covered much longer distances of up to 30-50 km and beyond to access medical care at the service locations of the HIV-care clinics and, in so doing, they bypassed HIV-health facilities that are proximate to their neighbourhoods. The explanation for this type of health-seeking behaviour may be two-fold. Firstly, it may relate to the HIV/AIDS-stigma which causes the caregivers to move farther away from the nearby HIV-care facilities where they may be identified or, secondly, it may be a demonstration of the phenomenon of 'bypassing' proximate health facilities to seek healthcare farther away, thought to be connected with patients' perception of better quality of care at higher-level hospitals (Kahabuka *et al.* 2011:315). Nonetheless, this health-seeking behaviour may also imply that caregivers place greater value on their medical condition *vis a vis* their oral health and thus allow greater preferences in health-seeking for medical care.

In addition to factors of distance to the point of service delivery, there is also the issue of time spent at the health facility, and forgone earnings which caregivers consider are important additional costs to consuming healthcare. They fear the loss of earnings from a day's *missed* work

incurred by the decision to visit a health provider. With the combined travel time to and from the health facility, as well as time spent in accessing healthcare, a trip to the health provider may well negate a whole day's worth of work, and income being lost from inability to work while at the health provider. The health workers in the study had observed that most caregivers had no one but themselves to run their informal businesses. In some instances, some resorted to paying other people to stand in for them but those deployed, even family members were not always dependable. According to Russell (2008:1), who reports on the demand-side factors of healthcare utilization in Ghana, individuals may work through sickness instead of going to health providers because of actual and time costs, as well as loss of income from a day's work for-gone. In addition, there are likely to be other considerations such as household chores which need to be taken care of while the caregivers are at the hospital seeking healthcare. Given the multiple roles played by women in many African cultures, household chores are likely to be a primary responsibility for the caregivers in this study as well. It would seem that compliance in health-seeking may be more easily improved in those who are not economically active since they are more likely to have time to attend for treatment; however, it is prudent to balance such views by the other far-reaching effects of low incomes.

According to the study findings, caregivers base satisfaction with quality of care, to a large extent, on the type of health facility that they visit, whether public or private. Some of the respondents are satisfied with the services they receive while others are not entirely satisfied. The ratings on cleanliness and maintenance of the oral health facilities were comparable for both categories of facilities, where sufficient levels of acceptability were recorded, *albeit* with better scores on facilities at the private dental clinics. The private dental clinics were also rated higher than the public oral health facilities in the quality of health services provided. The caregivers were

particularly impressed by the efficiency with which they were served at the private dental clinics, and the ease with which they were able to get appointments. They reported no queues at the private dental clinics, and in addition, medicines and other treatment facilities were readily available. To the caregivers, this demonstrates better organizational qualities in service delivery at the private clinics than at the public health facilities, as articulated in case narrative 6.2.1 (p. 103), where the caregiver states that she is more attracted to services at private facilities because of the 'good ways in which they offer their services'. Unfortunately, she was unable to afford the cost of care and therefore resorted to seeking oral healthcare in the public sector.

Frequently, when patients do not feel competent to judge the technical quality of health services, they base their satisfaction of quality of care on the timeliness with which they receive services and the promptness in being attended to by the doctors at the health facilities. Similarly, the caregivers in this study view waiting time before seeing the doctor as both a cost and a quality issue. The respondents reported that waiting time was more favourable at the private dental clinics where the average waiting time was 1-2 hours, compared to 3-5 hours that they would normally wait at public health facilities. One of the key informants gave his opinion on the bureaucracy and time-consuming processes which prolong waiting times for patients at public health facilities; according to his explanation, patients are required to queue at several service points from which they would not be able to proceed to the next counter until they have cleared with the previous one and, usually, there is congestion at each of these counters. In contrast, private health facilities had fewer processes and this expedited services at these institutions.

The long waiting times experienced at public healthcare facilities likely indicates distribution of staff and equipment that is not commensurate with the needs of the population who seek care at the institutions. Aday and Anderson (1974: 210) report that long waiting queues can influence the

frequency of attendance by the populace. In this study, the long queues at public health facilities caused the caregivers to have preference for treatment at the private dental clinics when they could afford it. According to the discussants, the longest queues at the public dental facilities happened at the registration points, the x-ray departments and the pharmacies which had convergence of patients seeking those services. Whereas the caregivers concede that healthcare services may be cheaper at public health facilities owing to government subsidy, they are deterred by the long queues which result in time wasting and increased opportunity costs. According to Anyanwu and Okeke (2014: 848), when clients are not satisfied with the quality of care, or they consider that the costs in resources, time and effort in accessing such care is not commensurate with the services given, and they resort to seeking care in other settings. The convenience of long opening hours including the week-ends at the private institutions was another incentive to visit those facilities and save on school hours for their school-going children.

The correct attitudes towards a client is likely to influence the preference for a particular health provider, thus the increasing calls for improving the interpersonal skills of health workers as part of addressing the quality of care at health institutions. There was a better score on the attitude of health workers at the private dental clinics than at the public health facilities. The responses were linked to client-nurse relationships which were described as very good at private dental clinics by 56% of the caregivers, while those who attended public health facilities scored a much lower rating of 22%. According to the caregivers, some health workers at the public institutions were rude and impatient, consequently, creating an unfriendly atmosphere at these institutions; further, they were perceived to have poor verbal communication with those seeking health services. Notwithstanding, the caregivers are cognizant of the enormous workload placed on the health workers by the high influx of patients at these institutions, and this, they opined, could possibly have an effect on the

health workers' poor attitudes. Anyanwu and Okeke (2014:847) posit that understaffing at health facilities is a component of health policy decisions and the provider-health consumer ratio which, if not well balanced, could result in health workers' poor attitude towards their work; regardless of how good a health worker may be, increased and constant workload will likely lead to a decline in attitude and possibly ignite burn-out in the patient. If the influx of patients to a health facility is marked with inflow of additional health facility workers, then health workers may not feel the extra workload.

Interestingly, the private oral health facilities were not always considered superior in provision of quality healthcare services by the caregivers. The discussants were of the opinion that the qualifications of some of the doctors at the private dental clinics are questionable and, therefore, the public institutions offered the recompense of having large numbers of medical experts and specialists; the only drawback being the recurring absenteeism of the doctors at these public facilities which necessitated that patients sometimes follow the doctors to their private clinics in order to obtain treatment, *albeit* at a higher cost. Andaleeb (2000:96) states that private hospitals are not subsidized and depend on income from clients (market incentives). Therefore, they are more motivated than public hospitals in providing quality services to meet patients' needs more effectively and efficiently. In conclusion, the study findings do not *decisively* demonstrate whether private or public health facilities are the most satisfactory among the caregivers for the utilization of oral healthcare. Instead, each category of facility has pros and cons that are based on geographical accessibility, prices of care, long queues and timely services, availability of medicines and specialist services, and health workers' attitudes.

CHAPTER EIGHT

SUMMARY, CONCLUSION AND RECOMMENDATIONS

8.1 Introduction

This chapter presents a summary of the study findings and draws conclusions from the findings. The chapter also provides recommendations based on the study findings and makes suggestions for further research.

8.2 Summary

8.2.1 The health care utilization model

This study provides an opportunity to understand the complex phenomenon and multifaceted human behaviour in the utilization of oral healthcare among a cohort of female caregivers of children with HIV/AIDS. It was guided by Anderson's behavioural model of health service utilization which captures the characteristics of an individual and their ability to access available resources to utilize health services. The model presupposes that healthcare utilization involves an interaction of individual predisposing, enabling and need factors which are influenced by societal determinants and outcomes of the utilization of formal health services, making it recursive in nature. On the basis of this model, the study variables were classified as caregivers' predisposing factors (age, marital status, education, occupation, oral health culture, attitudes and practices), enabling factors (income, geographic location of health facility, transportation, prices of care, health insurance, social networks and religion), healthcare system factors (type of facility, cleanliness and maintenance, waiting time, availability of drugs, attitude of health workers), and need factors (perception of dental illness, symptoms of pain, impact on quality of life, treatment preference). The findings of the study demonstrate the dynamic interplay of these factors among

the caregivers, and their direct and indirect effects on the utilization of oral healthcare for children with HIV/AIDS.

8.2.2 The influence of perceptions and culture on oral healthcare utilization

The study findings reveal that caregivers' perceptions and cultural practices frequently lead to delay in utilizing oral healthcare for children with HIV/AIDS. Among the caregivers, children's first teeth are considered to be temporary teeth and, for that reason, treatment is deemed unnecessary and is frequently delayed. In addition, discolourations on children's teeth are attributed to their use of ARV medication, therefore, not viewed as an illness that requires medical attention. The culture of oral healthcare utilization for the children is problem-oriented and mainly for the relief of toothache, where extraction of the offending tooth is the preferential treatment and precludes the use of preventive oral healthcare. While utilization of oral healthcare is mainly undertaken for the relief of pain, the outward show of white and good alignment is important to the caregivers and impacts on their self-esteem and social interaction. Thus, the concern for aesthetics and appearance has a role in motivating some caregivers to utilize oral healthcare. The caregivers have strong beliefs in myths and folklore surrounding the 'teething' process in infants; for instance, they link the occurrence of diarrhoea and fever directly with the eruption of milk teeth. They also subscribe to the excision of the so-called 'plastic' and/or 'nylon' teeth in babies, for which they access the services of traditional healers or other cadre of trained women, following the advice of elders in the family. From time to time, the older caregivers engage the use of traditional herbs to relieve the symptoms of teething, and home remedies as first-aid measures to relieve pain and swelling from the teeth or gums. Some of the caregivers believe in cleansing ceremonies to dispel bad omen brought about by a child who is born with natal or neonatal teeth. These beliefs

among the caregivers are considered to be at variance with biological knowledge and information. However, the caregivers are socialized to believe in them and, therefore, they seek alternative forms of treatment when they deem it necessary.

8.2.3 The impact of socioeconomic conditions on oral healthcare utilization

The proportion of children in this study who did not utilize oral healthcare was above the national average for non-utilization of oral healthcare services by children. The caregivers perceive oral healthcare services to be unaffordable against their meager earnings which are often irregular and unpredictable. In addition, they have competing household expenses, a common challenge among low-income earners. The mode of payment for oral healthcare services is mainly from out-of-pocket (OOP) expenditure, and oftentimes, they are subjected to financial risk from health expenditure. Further, there is no evidence of robust universal health coverage to ensure quality health services without risking financial hardships from unaffordable out-of-pocket payments; instead, the caregivers have poor enrollment with NHIF due to misinformation and perceived burdensome operations of the scheme. These factors serve to constrain the timely and appropriate utilization of oral healthcare. The resulting pattern of utilizing oral healthcare services for children with HIV/AIDS is indiscriminate and *ad hoc*, without a usual source of continual care. The caregivers, instead, seek the services of oral health providers that are conveniently located or recommended through their social networks. In contrast, they have regular source of medical care for HIV/AIDS for which they enroll their children at designated HIV-care clinics for regular follow-up, while lacking the same perception in utilizing oral healthcare. This is clear demonstration of insufficient oral health awareness and literacy that creates an unfelt need and/or lack of opportunity to utilize regular oral healthcare and preventive services. The caregivers also

perceive a deservedness to free oral health services for themselves and their children, in the same way that they receive free medical care at the HIV-care clinics. Further, some of the caregivers suffer from HIV/AIDS stigma and perceive biased care whilst utilizing oral healthcare. Consequently, they are careful not to disclose their HIV-positive status when they visit the oral health provider.

8.2.4 The significance of structural factors in oral healthcare utilization

The choice of an oral health provider involves the interplay of several factors. It emerged that service location and distance covered to the health facility are the most defining factors of accessibility among the caregivers and, therefore, are significant determinants in selecting their oral health providers. The small, privately-owned dental clinics located within the vicinities of their neighbourhoods were the most popular oral health facilities; in effect, the caregivers walk or use quick means of public transport to these facilities, and thus, they curtail transport costs and inconveniences of modes of travel. There is strong influence of social networks among the caregivers in passing on health information, particularly on the selection of appropriate oral health providers. The private oral health facilities are viewed to be better organized, more efficient in providing services, and to have better amenities than public oral health facilities in addition to having extended operating hours which was suitable for their children's treatment after-school hours. Their dissatisfaction with public health facilities emanates from the long queues, long waiting times, unavailability of drugs and the poor attitude of some of the health workers at these institutions, where time spent is seen as forgone earnings due to loss of income from a missed work. Ultimately, caregivers trade-off user-cost of care with perceived quality of care at the health

facilities, choosing oral health providers that offer them the greatest convenience. Figure 8.1 presents a diagrammatic summary of the study findings.

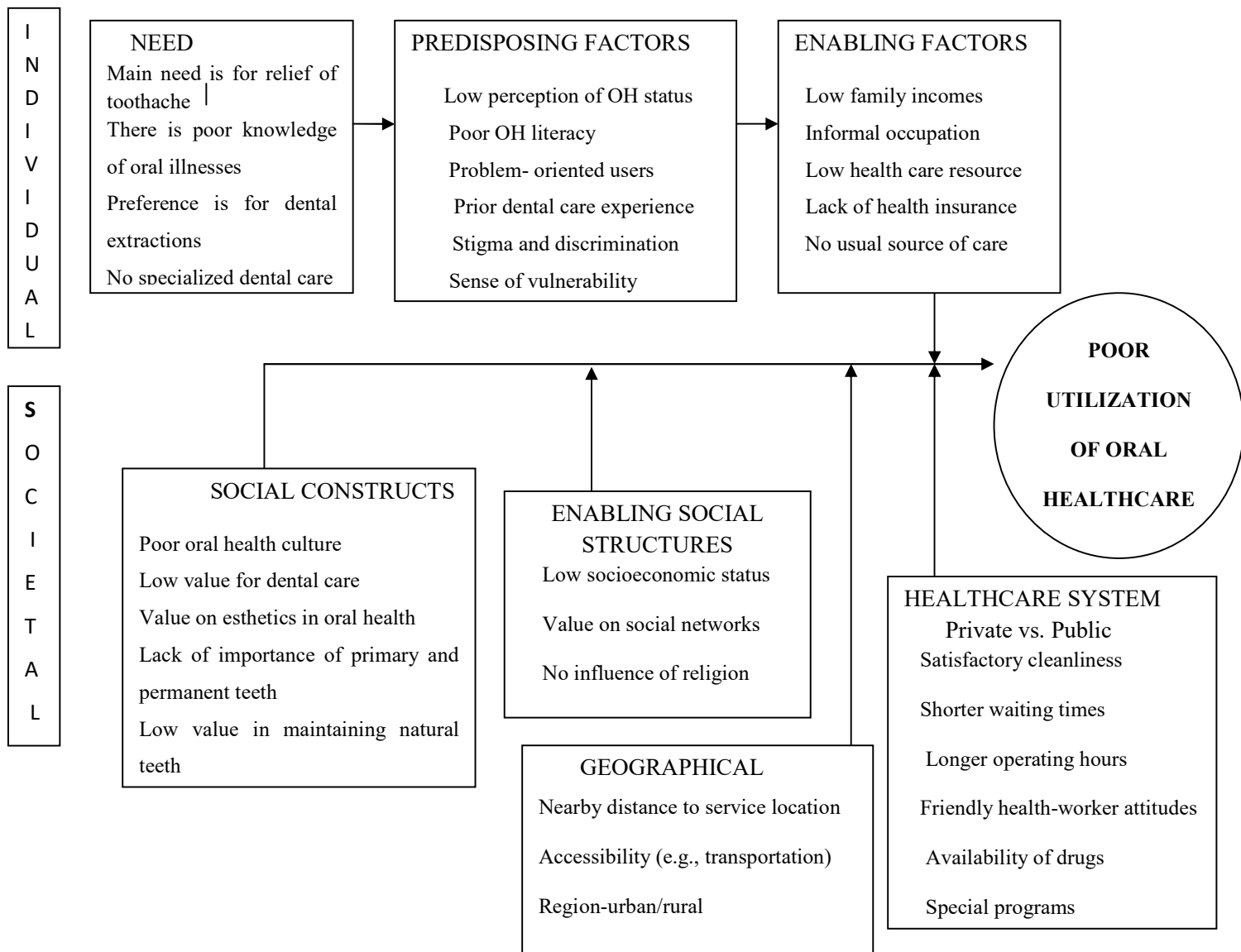


Figure 8.1: Summary of the determinants of the utilization of oral healthcare among caregivers for children with HIV/AIDS (Source: Survey & qualitative data, 2016)

8.3 Conclusion

The study sought to establish the determinants of the utilization of oral healthcare for children with HIV/AIDS among a cohort of caregivers attending HIV-care clinics in Nairobi City County. On the basis of the study findings and discussions, the conclusion can be drawn that the caregiver's decision to utilize oral healthcare for their children is not an isolated event; rather it is a composite of their perception on oral health and dental illnesses, cultural forces, socio-economic circumstances, and structural factors of the healthcare system.

Firstly, the caregivers have prevailing perceptions and cultural beliefs about oral health and illness management that are holistic and woven into the social fabric of their daily lives and, these beliefs, often delay the utilization of formal oral healthcare for children with HIV/AIDS.

Secondly, the socio-economic circumstances of the caregivers have both direct and indirect effects on the utilization of oral healthcare. The lack of robust universal health coverage and poor participation in NHIF, aggravated by the out-of-pocket mode of payment for oral health services is a key determinant of the poor utilization of oral healthcare for children with HIV/AIDS.

Thirdly, the structural factors of the healthcare system, in particular, the distance to the service location significantly determine the choice of oral health providers. The perceived qualities of care and organization of services at the private dental clinics sometimes trump the lower costs of care at public health institutions because of quick appointments, shorter queues, shorter waiting time, friendlier health worker attitudes, and extended operating hours.

8.4 Recommendations

1. There is need for the National government to formulate policy to support basic oral healthcare services for children with HIV/AIDS within the framework of comprehensive healthcare delivery and in the context of caregivers' cultural construction.

2. There is need for National government to make available more robust universal health coverage through greater government subsidy on health insurance and to create pro-poor payment plans to enable low-income earners and those in the informal sector benefit from public health insurance in the utilization of oral healthcare.

2. There is need for the County government to take oral healthcare services closer to the people by establishing satellite dental clinics at the grassroots with adequate operating hours, to reduce distances travelled and enable access to oral healthcare at *regulated* public health facilities.

8.5 Further research

1. Collaborative research and development of innovative models that enhance timely utilization of oral healthcare for PLWHA within the framework of comprehensive healthcare delivery at the HIV-care clinics. These should address cultural and other barriers to access of oral healthcare that are identified in this study.

2. A detailed cost analysis of providing a basic package of oral healthcare for children with HIV/AIDS. This should include determination of the role of cost in utilizing oral healthcare for children, stratified by the income levels of PLWHA.

EPILOGUE

MY JOURNEY IN MEDICAL ANTHROPOLOGY

9.1 Introduction

This chapter gives a brief description of my journey in the hitherto uncharted waters of the social sciences. It begins with the preliminaries of crystallizing my ideas on what I wanted to study, while at the same time addressing the uncertainties raised by naysayers. This is followed by the insights and ‘take home’ learning lessons from the study findings and, finally, a portrayal of my experiences as a social sciences researcher.

9.2 My journey

But is it really a science?

Too often I found myself defending my choice of PhD study against the conceived notion that Medical Anthropology is a ‘soft science’ with no real benefit to my biomedical training in patient oral healthcare. I could well understand the concerns of my colleagues because, coming from a biomedical research background, my proposed research was generally not considered to be based on rigorous experimentation and exact mathematical predictions, where ‘science’ connotes precision and definite boundaries, compared to the less well-defined boundaries of the social sciences. However, I was not deterred. Having been a paediatric dentist with training in the ‘formal’ oral healthcare of children, and a career spanning over 25 years, there was a sense in which I wanted to delve above the typical experimental sciences and clinical studies and do something that would broaden my horizon in the care of my patients. I became interested in the social determinants of health and disease and why patients behave the way they do in utilizing oral healthcare. My background reading revealed that the social sciences, whilst they may not

establish measurable criteria or make mathematical predictions in the manner that we were accustomed to because of the degree of interactive/adaptive complexity of the systems involved and the qualitative nature of the analysis applied, they are nonetheless 'real' sciences carried out on the basis of sound scientific investigations and, possibly, have a more important effect on the day-to-day life of humankind than the so-called 'hard' sciences.

As doctors, the duality of being a scientist as well as the humanness of the profession gives us one of the most remarkable jobs in the world. Unfortunately, oftentimes we do not always realize that culture affects the humanity aspects of being a doctor. Through my journey in this research, I have come to realize that we, as health providers, are confined by our own culture which is mostly made up of biases and limitations. We tend to regard what we do in treating patients as the 'logical' *vis a vis* the 'irrational' beliefs of our patients. We visualize our patients as being 'ill', 'uninformed' and 'weak', against ourselves who are 'well', 'educated', 'strong' and having the science to provide cure for their illnesses. Thus, we oftentimes fail to appreciate the cultural framework in which our patients have been socialized which gives them, every so often, a completely different view of what disease is, a different ideology of the disease process and an opposite take on what culture thinks of the disease and its treatment. When this happens, there is a cultural 'clash' with the doctor and we heap blame on our patients and label them as 'non-compliant'. For us dentists in particular, who deal with physical affliction whose outcomes cause mechanical problems to be 'fixed', it is easy to perceive culture as having nothing to do with it.

My journey in medical anthropology brought me to the realization that when the historic and situational facts of people's socialization are considered, one understands that their perceptions and beliefs are not crazy, but that patients have them for a reason. The patients endorse certain

constructs, cultural relativism and sense of subjectivity, which gives them a view different from that of the western biomedical culture. For example, whereas my medical discipline has depths of information on the value of maintaining a functional deciduous dentition and the repercussions of having the first teeth in children lost too early, the respondents in my study have a completely different opinion of this understanding. They are socialized into believing that these teeth are *temporary* and are present in the oral cavity only for a limited period, thus having no real value other than paving way for the permanent teeth. Therefore, they uphold the view that dental treatment for young children is not justified and only incurs unnecessary health expenditure. Another illustration of culture at cross-roads among the caregivers in my study is the practice of excising ‘nylon’ teeth in infants where, according to me; there is no scientific value in doing so. However, according to traditional myth and folklore, there are worms embedded in the prominent canine tooth buds of infants, which cause them to suffer from severe childhood illnesses that could be fatal. When they are turned away by oral health providers who have the ‘scientific’ knowledge about the phenomenon, the caregivers leave and search for the alternative services of traditional healers who ‘see’ things from their point of view and are willing to carry out extraction of these ‘teeth’, *albeit* in the most dubious conditions and sometimes, with precarious outcomes. It was apparent in my study that patients are constantly navigating the confusing medical environment and, oftentimes, their only source of information is from their circulating social networks with the unfortunate outcome being continued tolerance of illness and disease. For instance, the respondents in my study strongly believe that dental caries is not an illness, but instead, it is caused by the chronic use of ARV medication. It is, therefore, normal to caregivers that children with HIV/AIDS have these ‘blackish teeth’. This perception is perpetuated among

their social circles until it is believable, consequently, denying them the opportunity to learn of the benefits of treatment.

My journey also taught me that, apart from biocultural adaptability, health and illness are greatly shaped by other multidimensional factors and ecological perspectives which, oftentimes, we as 'medics' are completely oblivious to. Individuals set out to formulate perceptions and behavioural intentions whilst negotiating their social environment against broader structural backgrounds. In this instance, the caregivers were of middle-low to low socioeconomic status with individual attributes of low education, low family incomes, and poor oral health literacy; they were mainly engaged in occupations of informal nature with irregular incomes and competing priorities on the use of household expenses. These challenges were further intercepted by societal contexts such as deficiencies in the structure and function of the healthcare system, and lack of formalized social welfare mechanisms or robust universal health coverage that provides them with a safety net for easier access to healthcare. There were difficulties in affordability of oral healthcare services and procurement of transport fares, whilst payment for oral health services was mainly from out-of-pocket expenditure which frequently put them at financial risk when spending on healthcare. These factors resulted in fragmented, poorly harmonized oral healthcare services for children sourced at random nearby privately-owned oral health facilities that were likely to be unregulated and/or unvetted. The children did not have a usual source of continual and/or preventive care at regulated oral healthcare facilities. In the context of endemic poverty, societal factors ultimately constrained the ability of caregivers to utilize oral healthcare in a timely and efficient manner.

My journey through medical anthropology suggests that it may be time for doctors to rid the term 'compliance' and, instead, adopt a model that assists patients to understand that, as powerful as

culture is, biomedical care is equally powerful in treating their illnesses. This involves closing the gaps of information and looking at where we can reconcile our ‘cultural’ differences. As health providers, we need to adopt a broader approach to patient-care in which we may perhaps be seen as *healers*, rather than doctors who cure disease. A healer encompasses the whole patient, cures the illness and makes the patient want to come back, thus, they become compliant. An important take-home point for me was that patients have valid reasons for the perceptions and beliefs that they hold and, therefore, doctors cannot effectively treat patients without understanding what the potential barriers to the utilization of healthcare are, be they cultural and/or societal.

So, what was it like, to actually carry out this research in medical anthropology in dissimilarity to other research work that I have done previously? From this perspective I would describe my journey as liberating, exciting and even relaxing in many respects. For instance, from its broad emphasis on humankind and culture, one can include just about anything to study in anthropology, that is, there is more freedom and creativity in coming up with ideas and design. The qualitative methods of data collection presented me with a unique way of seeing the world through somebody else’s eyes, and I gained immensely from it. I quickly discovered during my field work, that the outlook anthropologists adopt towards the world, by necessity, was one of tolerance, understanding, and absorption due to the informal approach of the fieldwork process. It was interesting for me to acquire the unusual role of a ‘listener’, but once I relaxed, I thoroughly enjoyed the interactive nature of the focus group discussions (Figure 9.1). The discussants appeared to appreciate the time I spent with them learning about their experiences, and they readily confided in me, although with the expectation that I was there to mediate between them and the healthcare system in resolving their oral health problems. Listening to the case narratives and the challenges faced by the women in the utilization of oral healthcare particularly was, for

me, an emotive process. The process of writing up my thesis was also a learning curve. I was shown how to present my ‘study findings’ in a manner that was clear and comprehensible to the reader, rather than having mere tabulations of data and explanatory texts.



Figure 9.1: Focus group discussion in session with PI

Finally, I want to affirm that my journey through medical anthropology was extremely rewarding, and I wouldn't have done my study otherwise. Many of us choose to become doctors because we want to treat our patients of their illnesses. However, seeing through fresh eyes, my research in medical anthropology has provided me with a more intense route of getting to know the people for whom I strive to provide healthcare. My journey may thus be summed up by one of the inspirational quotes of William Osler, an icon of modern medicine:

“Ask not what disease the person has, but rather what person has the disease.”

William Osler (1849-1919)

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APPENDICES

Appendix 1: Informed consent document

Introduction

The main aim of this study is to collect information on your beliefs in, and experiences in utilizing oral health care for your children. I am interested in understanding how culture, abilities and society influences the way caregivers of children with HIV/AIDS in Nairobi, utilize oral health care for their children. Please answer the questions as truthfully as possible. The information collected from you will be strictly private and confidential and intended for research purposes only. I kindly request you to read this form and ask any questions that you may have before agreeing to participate in the study, and confirm your willingness to participate as a respondent by writing down your initials in the space provided below.

Participant Statement

I, (write initials).....confirm that I have understood clearly the information given on what being a respondent in this study on the determinants of the utilization of oral healthcare among caregivers of children with HIV/AIDS entails . I am convinced that no harm or unforeseen dangers will occur in the course of the study, and therefore do hereby freely consent to participate as a respondent.

Witnessed by (Researcher).....Signature.....Date.....

Thank you for your cooperation.

Appendix 2: Survey questionnaire

Introduction

Good morning/ afternoon

My name is Mary Atieno Masiga. I am a dentist with special interest in the oral health of children. Currently, I am a student at the Institute of Anthropology, Gender and African Studies (IAGAS) at the University of Nairobi, pursuing a Doctor of Philosophy degree (PhD). I am conducting research on how caregivers of children with HIV/AIDS perceive the oral health status of their children, and how they utilize oral healthcare. The information that I am collecting today can help the Nairobi County government address some of the challenges that caregivers experience while seeking oral healthcare for their children from the health facilities.

You have been identified and selected to participate in this study. I will ask you some questions to help us meet the objectives of this study. I request you to answer the questions freely and truthfully. The information that you provide will be treated with utmost confidentiality and will be used for purposes of this research only.

Thank you for your cooperation

Instructions

Please fill in the correct answers in the blank spaces or tick whichever is appropriate

Background information

Identification..... **Date**.....

Place of residence

Ethnic background.....

Child age..... gender.....

1. Socio-demographic information

i. Would you mind telling me your current age?

1. 18-25
2. 26-33
3. 34-41
4. 42-49
5. 50 and above
9. Don't know

ii. What is your current marital status (if mother)?

1. Single
2. Married
3. Separated/ divorced
4. Widow
9. Don't know

iii. What is your relationship to the child?

1. Biological mother
2. Foster or adoptive parent (related), specify.....
3. Foster or adoptive parent (unrelated).....
4. Other, please specify.....
9. Don't know

iv. What is your highest school education?

1. No education
2. Primary school education
3. Secondary school education
4. Tertiary education (college)
5. Tertiary education (university)
9. Don't know

- v. What is your main occupation?
 - 1. [Record occupation]
 - 9 Don't know
- vi. What is the main source of income in your household?
 - 1. Salaried employment
 - 2. Informal employment
 - 3. Support from relatives
 - 4. Support from charities/donors
 - 5. Other, specify
 - 9 Don't know
- vii. What is the total income that your household gets every month from all sources?
 - 1. Less than or KES 10,000
 - 2. KES 11,000- KES 20,000
 - 3. KES 21,000- KES 30,000
 - 4. KES 31,000- KES 40,000
 - 5. KES 41,000- KES 50,000
 - 6. Above KES 51,000
 - 9 Don't know

2. Perceptions of child's oral health

- i. How would you describe the oral health of your child's teeth or mouth?
 - 1. Very good
 - 2. Good
 - 3. Fair
 - 4. Poor
 - 9. Don't know
- ii. Has your child ever had a toothache?
 - 1. Yes
 - 2. No
 - 9. Don't know

iii. Has your child ever had a mouth infection, swelling or bleeding gums?

1. Yes
2. No
- 9 Don't know

Skip to v if the answer is No)

iv. Would you say that your child's toothache or mouth infection comes?

1. Always
2. Often
3. Sometimes
4. Occasionally
9. Don't know

v. How much is your child's overall wellbeing affected by the condition of his/her teeth, lips, jaws or mouth?

1. Not at all
2. Very little
3. Some
4. Very much
- 9 Don't know

vi. Does your child have any marks on his or her teeth that won't brush off?

If not, go to viii)

1. Yes
2. No
- 9 Don't know

vii. Do these marks bother you (the caregiver)?

1. Yes
2. No
9. Don't know

viii. Does your child avoid eating some foods because of problems with his/ her teeth or mouth?

1. yes
2. No
9. Don't know

- ix. In the last 12 months, has your child had any fillings placed on his teeth?
1. Yes
 2. No
 9. Don't know
- x. In the last 12 months, have any of your child's teeth been removed because of tooth decay or 'gum boil' (abscess) or infection? Do not include teeth lost for other reason such as injury or trauma.
1. Yes
 2. No
 9. Don't know
- xi. In the past 12 months, have you or another adult taken time away from work or normal activities because of problems with your child's teeth or mouth?
1. Yes
 2. No
 9. Don't know
- xii. In the last 12 months, has your child taken time away from school or other normal activities because of problems with his / her teeth or mouth?
1. Yes
 2. No
 9. Don't know
- xiii. In general, compared to other children, do you think the appearance of your child's teeth is...?
1. Among the nicest
 2. Better than average
 3. Average
 4. Below average
 5. Among the worst
 9. Don't know

xiv. What is the best way that you can describe good oral health? (tick 2)

1. Teeth are white
2. Teeth are in a good line
3. Teeth are not rotten
4. Teeth are not painful
5. Mouth has no swelling
6. Other, specify
9. Don't know

xv. What measures did you take when your child experiences a toothache or mouth infection?
(Skip if the child has never had a toothache or mouth infection)

1. Visited the dental professional
2. Bought medicine from chemist
3. Treated with home remedy
4. Visited a traditional doctor
5. Other, specify
9. Don't know

xvi. How long did it take for you to seek treatment?

1. 1-2 days
2. 3-4 days
3. 5-6 days
4. after one week
9. Don't know

3. Experiences on the utilization of oral health care

i. Has your child ever visited the dentist for any treatment or routine dental care?

1. Yes
2. No
9. Don't know

If No, go to vii)

- ii. When was the *last* time that your child visited a dentist for any reason?
 - 1. Within the past year (less than 12 months ago)
 - 2. Within the past 2 years (more than 1 year but less than 2 years ago)
 - 3. Within the past 5 years (more than 2 years but less than 5 years)
 - 4. Five or more years ago
 - 9. Don't know
- iii. What was the reason for the *last* dental visit?
 - 1. He/she had pain in her teeth
 - 2. He/she had a swelling /ulcer in her mouth
 - 3. He/she went for a check-up
 - 4. Other, specify
 - 9. Don't know
- iv. What treatment did your child have when they last attended?
 - 1. Check-up
 - 2. Tooth extraction
 - 3. Dental filling
 - 4. Cleaning
 - 5. Medicine
 - 6. Other, specify
 - 9. Don't know
- v. Who paid for the dental services that your child had at the clinic?
 - 1. Self/ cash
 - 2. Employer insurance
 - 3. Personal dental insurance
 - 4. Charity/ donor aid
 - 5. Friends & relatives
 - 9. Don't know
- vi. How affordable were the dental services?
 - 1. Very expensive
 - 2. Expensive

- 3. Affordable
- 9. Don't know

vii. When was the last time that you (caregiver) saw a dental professional for yourself?

- 1. I have never attended
- 2. Within the last 12 months
- 3. Between 12 months and 5 years
- 4. Over 5 years ago
- 9. Don't know

viii. Are you and/or your child enrolled with a regular dental service provider?

- 1. Yes
- 2. No
- 9. Don't know

ix. Do you have any health insurance cover?

- 1. None
- 2. Employer cover
- 3. Personal cover
- 9. Don't know

x. Do you have NHIF insurance cover? (if yes, skip next question)

- 1. Yes
- 2. No
- 9. Don't know

xi. What are the reasons why you don't have NHIF insurance?

.....

xii. What are the main reasons why your child has not visited for any dental treatment in the last 12 months?

.....

4. Health care system specific factors

(Skip if child or you (caregiver) have never attended for oral health care)

- i. Thinking about the times that either you or your child have attended for dental care, which kind of dental facility did you seek treatment?
 1. Government hospital
 2. Private hospital
 3. Private clinic
 4. Mission/ charitable clinic
 5. Traditional/ herbalist
 6. Other, specify
 9. Don't know

- ii. What factors make you select the facility that you attended? (Tick 2)
 1. Charges for treatment are fair
 2. The facility is nearby
 3. Employer/insurance arrangement
 4. I get an appointment easily
 5. It was recommended
 6. Other, specify
 9. Don't know

- iii. Approximately, how far is the dental facility that you attended from your home?>1 km
 1. 1-5 km
 2. 6-10 km
 3. 10-15 km
 4. >15km
 9. Don't know

- iv. What mode of transport do you usually use from your home to the dental clinic?
 1. Walk
 2. Matatu/buses
 3. Motorbikes

4. Motorbikes & matatus
 5. Private car
 6. Taxi
 9. Other, specify
- v. How much time do you usually spend at the facility from arrival to the time you leave after treatment?
1. <1 hour
 2. 1-2 hours
 3. 3-4 hours
 4. >4 hours
 9. Don't know
- vi. Does the dental health facility open & close conveniently for you?
1. Yes
 2. No
 9. Don't know
- vii. What is your opinion on the cleanliness & maintenance of the dental facility that you attended?
1. Very Good
 2. Good
 3. Average
 4. Below Average
 9. Don't Know
- viii. Are you satisfied with the oral health services that you got at the dental facility that you attended?
1. Yes
 2. No
 9. Don't know

ix. How would you describe the attitude of your oral health service providers?

- 1. Very good
- 2. Good
- 3. Average
- 4. Below average
- 9 Don't know

x. Would you voluntarily inform the dental professional on the HIV status of your child/yourself?

- 1. Yes
- 2. No
- 9. Don't know

xi. If not, why not?

.....
.....

xii. Would you like to share any other personal, cultural or societal beliefs about oral health and the utilization of oral health care?

.....
.....

Thank you very much for your time.

Appendix 3: Focus group discussion guide

1. Challenges in caring for children with HIV/AIDS.
2. Cultural and religious beliefs and children's dental problems.
3. Status of child's oral health.
4. Treatment of dental illnesses.
5. Decision-making in seeking healthcare.
6. Challenges faced in accessing oral healthcare.
7. Payment for children's dental treatment.
8. Health insurance.

Appendix 4: Key informant interview guide

1. Healthcare services offered at the HIV-care clinics?
2. Oral health care for children with HIV/AIDS.
3. Health information to caregivers of children with HIV/AIDS.
4. Psycho-social challenges of caregivers who attend the HIV-care clinics.
5. Utilizing oral healthcare for children with HIV/AIDS?
6. Facilitation of oral healthcare for children with HIV/AIDS.

Appendix 5: Case narrative guide (probing points)

1. Living with a child/ children with HIV/AIDS.
2. Health information about dental diseases
3. Challenges in utilizing oral healthcare for yourself/child.
4. Coping mechanisms in utilizing oral healthcare.

Appendix 6: Observation checklist

| Item of Observation | Rating |
|---|---|
| 1. Ease of accessibility of HIV-care clinic | 1. Easy 2. Fair 3. Difficult |
| 2. Cleanliness & Maintenance | 1. Very Good 2. Good 3. Average 4. Below average |
| 3. Staff attitudes & patient interaction | 1. Very Good 2. Good 3. Average 4. Below average |
| 4. Giving oral health talks to patients | 1. Always 2. Sometimes 3. Never |
| 5. Opening hours of health facility | 1. Adequate 2. Not adequate |
| 6. Average time spent at health facility | < 1 hrs 2-3 hrs >3 hrs |