ORAL HEALTH FOR YOUNG ADULTS LIVING WITH HIV:

AN EVALUATION OF ORAL HEALTHCARE NEEDS

by

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ABSTRACT

ORAL HEALTH FOR YOUNG ADULTS LIVING WITH HIV: AN EVALUATION OF ORAL HEALTHCARE NEEDS

Noreen Myers-Wright

Background: Social and health supports provided during young adulthood can have long lasting health implications. Racial and ethnic minorities will soon comprise the majority of this population in the US and are more likely to experience poverty with poor access to health services. Oral health has been identified as a health disparity for young adults in the general population as well as those living with HIV (YALWH). Identifying and addressing barriers to oral healthcare are important for the long-term improvement of overall health outcomes for YALWH.

Methods: This mixed methods cross-sectional study includes: 1) an in-person quantitative survey and a semi-structured qualitative interview of YALWH between the ages of 17 and 25 years of age, 2) an online and in person survey of general and pediatric

dentists and clinical dental hygienists and 3) a focus group with dental clinic support staff of a hospital based dental clinic.

Results: YALWH expressed the importance of oral health in their lives; a clean mouth and straight white teeth impacts how they judge others and, they assume, how others judge them. Barriers to care identified across all study groups included dental insurance, HIV disclosure and dental fear.

Conclusions: Oral healthcare for YALWH can be affected by individual and systemic factors including provider communication skills, provider knowledge of HIV, limitations of healthcare delivery systems and the expectations of the individual patient. These factors are important considerations for health policy makers and oral health professionals in their efforts to address oral health disparities for YALWH.

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TABLE OF CONTENTS

Page

LIST OF TABLES

LIST OF FIGURES

Chapter I

INTRODUCTION

The educational, economic, social, and health supports provided during young adulthood between 18 and 26 years can have profound long-lasting implications. It is well established that efforts to better equip young adults to assume adult roles, develop marketable skills, and adopt healthy lifelong habits benefit them in many ways. The segments of the young adult population that are living with chronic diseases have an even greater and urgent need for comprehensive support. Unfortunately, this subset of young adults is frequently not prioritized as a distinct population in policy efforts, program design, and research (National Research Council [NRC] and Institute of Medicine [IOM], 2014). As such, disparities in health continue to persist among young adults in the United States. This dissertation examined one area of known health disparity for young adults: oral healthcare (NRC & IOM, 2009, 2014).

Young adulthood is a time of life in which significant physical, emotional, and psychological changes take place. It is a time that offers youth opportunities to establish patterns of health behaviors, which can affect health outcomes in their adult years. Events and influences of adolescence and young adulthood can affect the course of future health outcomes (Mulye et al., 2009). Youth specifically between the ages of 15 and 24 years, experience the effects of puberty and brain development that facilitate the transition to adulthood. This transition is modified by economic and social factors such

as family support, safety in schools, and peer support (Viner et al., 2012). Further, young adults often make health choices with limited abstract reasoning skills, a sense of invulnerability, and strong peer influence susceptibility (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). The strengthening of primary care services, such as the coordination of interdisciplinary services, the provision of confidential care, and financial support for healthcare services, could together assist young people to make better health choices. These changes would also lead to improve healthcare for those with chronic illnesses such as Human Immunodeficiency Virus (HIV) (NRC & IOM, 2009).

Poor health indicators typically characterized in young adulthood include engagement in aggressive and violent behaviors including homicide, unintended injury, substance use or abuse, drinking and driving, and sexually transmitted diseases (Mulye et al., 2009; Neinstein, 2013; Park, Mulye, Adams, Brindis & Irwin, 2006). More specifically, this age group experiences poor risk perception and the least access to healthcare and health insurance coverage, resulting in a range of poor health outcomes, including the transmission of HIV (Neinstein, 2013; Park et al., 2006). In addition, young adults in the general population and those with HIV frequently only access dental care on an as-needed basis, often in hospital clinics or emergency departments (EDs). Costly ED treatments include palliative care for dental decay or periodontal infections that have become intolerable (Bachman, Walter, & Umez-Eronini, 2012; Wall & Nasseh, 2013). The National HIV/AIDS Strategy (NHAS) for the United States includes improving access to care and health outcomes for HIV positive individuals and takes into account oral health as well as general healthcare. Oral health has frequently been

identified as an unmet need for people living with HIV/AIDS (PLWHA), and the unmet need for oral healthcare may be more prevalent than unmet medical needs (Dobalian et al., 2003; Freed et al., 2005; Heslin et al., 2001; Jeanty et al., 2012). The utilization of patient-centered medical homes may increase the coordination of care and improve overall health outcomes (Yehia & Frank, 2011).

HIV and Adolescence

Prior to 1995, an HIV diagnosis carried a higher likelihood of death from Acquired Immunodeficiency Syndrome (AIDS); however, due to the success of Highly Active Antiretroviral Therapies (HAART) and Combination Antiretroviral Therapies (cART), the number of perinatally infected infants has decreased, and teens and young adults infected with HIV are now able to survive longer with strict medication regimens (Vermund & Hayes, 2013). In the United States, we are witnessing the unexpected survival of children infected with HIV and consequently a growth in the number of young adults living with this virus. Youth ages 15-24 years infected vertically from a parent, from high-risk sexual activities, or from intravenous drug use face a life with a compromised immune system that includes daily medications and frequent co-occurring illnesses (Foster, Waelbrouck, & Peltier, 2007; Tanney, Naar-King, Murphy, Parsons, & Janisse, 2010).

The welcome advances in HIV therapies are tempered by the limitations of our healthcare system's ability to provide complete medical care in a youth-friendly environment (Tanner et al., 2013). Adolescents younger than 15 years of age are frequently dependent on their parents to organize their HIV care; however, young adults

17-24 years of age often need to navigate healthcare networks on their own with inadequate experience or health literacy levels (Tanner et al., 2013; Vermund & Hayes, 2013). Oral healthcare has been one of the specialized services identified as difficult to access for young adults in the general population as well as those living with HIV/AIDS (Atkins, Sulik, & Hart, 2012; Bednarsh, Reznik, & Tobias, 2012; Fox et al., 2012; Marcus et al., 2000; NRC & IOM, 2009; Rajabiun et al., 2012; Yu, Bellamy, Schwalberg, & Drum, 2001).

The perceived oral health needs of adults living with HIV/AIDS have been examined in recent studies, with 48% of participants reporting they could not access oral healthcare when needed and citing an inability to pay for oral health services as the main reason for not receiving care (Fox et al., 2012; Mofidi & Gambrell, 2009; Rajabiun et al., 2012; Walter et al., 2012). Further research found gender, race/ethnicity, living situation, and smoking status to be correlated with oral health quality of life among poor people living with HIV (Tomar, Pereyra, & Metsch, 2011). The importance of establishing routine medical and dental services during the transitional period from adolescence to adulthood and its potential to reduce the public health burden during adult and older adult years has been well documented (American Academy of Pediatrics [AAP], 2013; NRC & IOM, 2009; Okunseri, Okunseri Garcia, Visotcky, & Szabo, 2013). However, very few studies have examined access to and utilization of oral healthcare specifically for adolescents from 17 to 25 years old living with HIV.

Background

In addition to the many physical challenges associated with HIV, young adults living with HIV (YALWH) are also far more susceptible to the effects of the stigma associated with this disease than their adult counterparts (Hatzenbuehler, 2011). Many have had a lifetime of poverty and/or abuse and have contracted HIV as a result of survival strategies gone wrong (Clum et al., 2013; Dietz, 2013; Feldman & Middleman, 2003). Additionally, many perinatally infected children now transitioning to young adulthood are facing the social stigma associated with HIV for the first time in their lives (Chung, 2013; Halkitis & Figueroa, 2013).

Research has demonstrated that individuals living with and experiencing HIV-related stigma are five times more likely to report poor access to medical care (Smit et al., 2012). The Centers for Disease Control and Prevention (CDC) suggested that among those with HIV, young men who have sex with men (YMSM) are among the most marginalized and subjected to HIV stigma as well as sexual orientation stigma (Dowshen, Binns, & Garofalo, 2009). As such, YALWH - and YMSM in particular - are at risk for not seeking healthcare for either their HIV needs or other general health issues. Poor oral health thus remains a concern. YALWH represent a group that is sociodemographically diverse, has varied modes of HIV infection, and engages in a range of sexual and substance abuse behaviors (AAP, 2013; Foster et al., 2007; Tanney et al., 2010). Although much as been written about adults living with HIV (ALWH), including women and adults living in low-income neighborhoods, few studies currently exist that examine the factors contributing to the oral health disparities of YALWH (Bednarsh et al., 2012;

Freed et al., 2005; Marcus et al., 2000; Shiboski, Palacio, Neuhaus, & Greenblatt, 1999; Tomar et al., 2011). It should be noted that preliminary research has suggested that YALWH may experience unique barriers such as HIV-stigma sensitivity and dental fear experienced during a time of emotional and intellectual development (Philbin et al., 2013). Further, low rates of medication adherence have been correlated to low health literacy levels including knowledge of HIV, accessible treatments, and finding youth-friendly providers (Feldman & Middleman, 2003; Keiser Family Foundation [KFF], 2012; Manganello, 2007; Philbin et al., 2013).

In addition to providing comprehensive oral care, oral health providers are well positioned to identify symptoms of HIV that often appear first in the mouth. Indeed, Singer and colleagues (2012) reported that oral health professionals were more successful than medical examiners in identifying oral lesions associated with HIV/AIDS. The changing demographics of underserved populations, including YALWH, demand that present dental residents and practicing oral healthcare providers increase their abilities to deliver culturally competent care for patients with medical co-morbidities (Wagner & Redford-Badwal, 2008). Advanced Education General Dentistry (AEGD) and Pediatric Dentistry residents have the capacity to be key participants in future oral healthcare for YALWH. The AEGD residency programs are designed to prepare students to deliver general oral healthcare to patients with complex medical histories; the pediatric residency programs prepare students to care for children and adolescents (Commission on Dental Accredition, American Dental Association [ADA], 2007a, 2007b). Dental hygienists are trained to screen and assess the oral health status of all patients on an individual basis and

are also potential key players in the delivery of oral health services to YALWHA (Santella et al., 2013).

The use of Highly Active Antiretroviral Therapies and Combination Antiretroviral Therapies have reduced the prevalence of HIV-related oral lesions; however, oral lesions remain prevalent in patients who do not adhere to medication regimes as well as those who are undiagnosed. Oropharyngeal candidiasis remains the most common infection seen in People Living with HIV/AIDS (PLWHA) (Patton et al., 2013). Treatment adherence has been found to be a serious problem specifically for YALWH, underscoring the need for routine oral healthcare provision for adolescents and young adults living with HIV (Murphy, Wilson, Durako, Muenz, & Belzer, 2001).

In addition, staff members of dental teams often include reception or registration desk personnel and call-in center personnel. The interactions of patients with reception and call-in staff can impact patients' perceptions of overall quality of dental care and personal acceptance (Sheffield, 2009). Rajabiun and colleagues (2012) found that ALWH cited friendly staff and the dental setting as factors influencing their return for routine dental care. Tobias, Fox, Walter, Lemay, and Abel (2012) reported that patients' experiences at the dental office affected the level of patient retention. Sankar and Luborsky (2003) also found that PLWHA frequently reported the importance of "being treated like a human being" by the dental office team as a factor in utilizing dental care. Research documenting young adults' low utilization of medical care, particularly dental care, may support the importance of identifying factors that facilitate dental office staff's understanding of the needs of YALWH (Atkins et al., 2012; Mitchell et al., 2003; Mulye et al., 2009; Viner et al., 2012; Vujicic & Nasseh, 2014).

Logan, Guo, Dodd, Seleski, and Catalanotto (2013) reported that fewer than one in four dentists provide care for Medicaid patients. These decisions negatively impact the most vulnerable populations, including racial and ethnic minorities, those living in poverty, and Lesbian, Bi-Sexual, Gay, Transgender, and Questioning/Queer (LBGTQ) populations, all of which are frequently represented within the YALWH subgroup (Dowshen et al., 2009; Hatzenbuehler, Phelan, & Link, 2013; Logan et al., 2013). Some research has also suggested that in order to reduce dental disparities, present and future dental providers must be trained to be more responsive to the cultural needs of their patients (Wagner & Redford-Badwal, 2008). Cultural competence has been described as a set of knowledge-based skills that can enable healthcare providers to offer clinical care to patients from various ethnic or racial groups. The National Center for Cultural Competence has suggested that professional organizations adapt guidelines that enable medical professionals to work with culturally diverse populations (Behar-Horenstein, Garvin, Moore, & Catalanotto, 2013). Limited literature exists on dental professionals' cultural competence and perceived barriers to care for YALWH. This dissertation therefore sought to provide descriptive data on the perceived ability of pediatric and general practice dentists and dental hygienists to provide culturally competent care for YALWH.

Theoretical Framework

The survey instruments and structured interview guide utilized in the present study were based on constructs of Gelberg, Andersen, and Leake's (2000) Behavioral Model for Vulnerable Populations. A revision of the Behavioral Model that focused on

vulnerable populations, this model has been widely applied to health service research (Andersen, 1968). More specifically, the revised model focuses on vulnerable populations to predict and explain the utilization of health services and personal health behaviors. The conceptual framework of this model suggests that individual predisposition, enabling resources, need, and health behaviors are factors that predict the utilization of health services. Therefore, it was the intention of this study to consider how oral health behaviors and the use of oral health services by YALWH are determined by social structures such as housing security, food security, employment, education, and social networks; health beliefs such as healthcare normative behaviors, oral health literacy, and values regarding oral health; and personal resources such as insurance, perceived barriers, and regular source of care.

Problem Statement

Identifying and ultimately addressing barriers to oral healthcare are important if the overall quality of health outcomes for PLWHA is to be improved and maintained in the long term. The importance of examining the needs of young adult populations in particular is underscored by several factors, including their susceptibility to stigma, their increased likelihood of low adherence to medication regimes and HIV testing, and evidence suggesting that perceived social support results in improved health outcomes for this age group (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). The present literature reveals few empirical studies that focus on oral healthcare among YALWH. In addition, there is little work focusing on the social structures, personal resources, and

personal health beliefs that shape access and utilization of oral healthcare services among this population.

Study Aims

1. Describe the perceived value of oral healthcare services, oral health-related behaviors, and perceived barriers to care among a sample of young adults age 17-25 years old living with HIV.
2. Identify and describe social and personal health belief factors that may be associated with normative utilization of oral healthcare among this sample of YALWH.
3. Describe and compare HIV knowledge, perceived cultural competence, and perceived barriers to care for YALWH among three different groups of dental professionals, including pediatric and general practice dentists, and practicing dental hygienists.
4. Describe the perceived role played, as well as facilitators and barriers to oral healthcare services for YALWH, among a sample of dental clinic support staff, dental assistants, and registration desk staff members at an urban dental clinic.

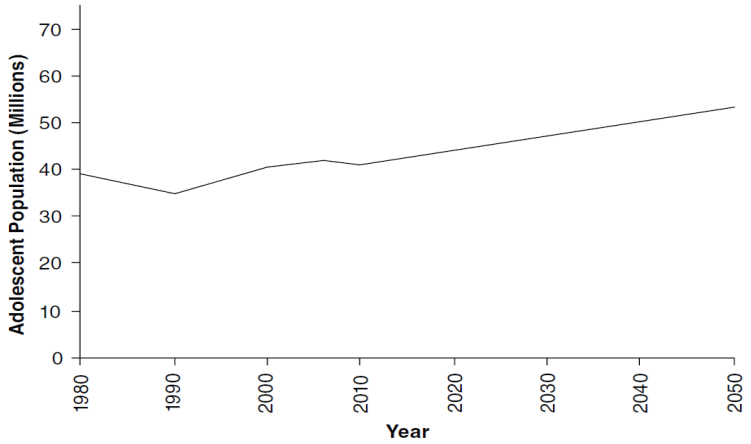
Chapter II

LITERATURE REVIEW

Demographic Changes

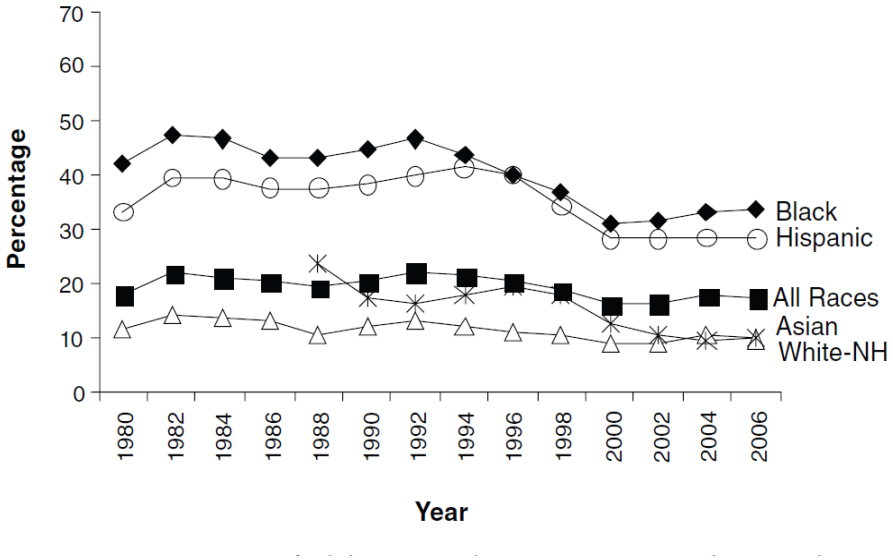
Young adult and adolescent populations in the United States (U.S.) are growing and are increasingly more diverse than older generations. It is estimated that the adolescent population, ages 10 to 19 years, in the U.S. will increase 28% by 2050 (NCR & IOM, 2009) (see Figure 1). Racial and ethnic minority youth will soon comprise the majority of the overall U.S. adolescent population and will be more likely to experience poverty and have poor access to health services (Mulye et al., 2009).

Hispanics living at or below the federal poverty level and with low education attainment have the greatest risk of being uninsured (AAP, 2013; Park et al., 2006) (see Figure 2). Lack of insurance contributes to increased disparities in access to and utilization of healthcare (Mulye et al., 2009; Park et al., 2006). As a result, we see disparities for access to care for health risks and illnesses such as obesity, diabetes, HIV, mental illnesses, and oral health diseases (NCR & IOM, 2009; Park et al., 2006).



Source: National Research Council (NRC) and Institute of Medicine (IOM). (2014). *Investing in the health and well-being of young adults.* Washington, DC: The National Academies Press.

Figure 1. Growth in the adolescent population, aged 10 to 19, 1980-2006 and 2006-2050 (projected)



Source: National Research Council (NRC) and Institute of Medicine (IOM). (2014). *Investing in the health and well-being of young adults.* Washington, DC: The National Academies Press.

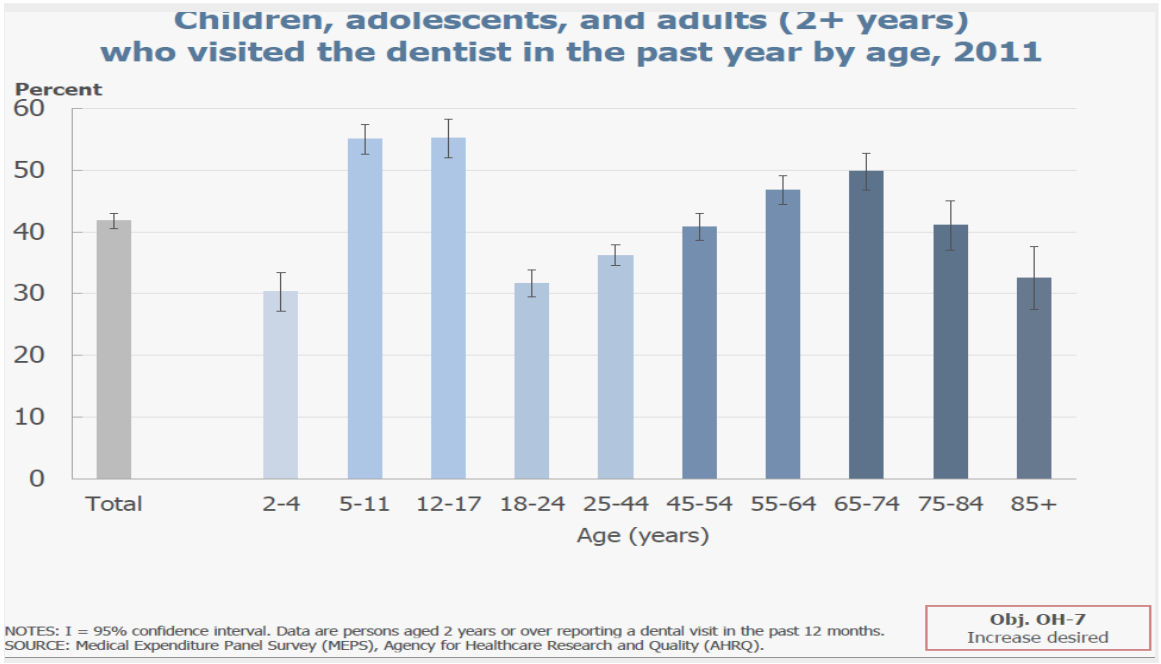
Figure 2. Percentage of adolescents under age 18 in poverty by race/ethnicity, 1980-2006

Oral Healthcare Services

As of 2009, the young adult population in the U.S. had the lowest number of dental visits compared to younger and older age groups (see Figure 3). Moreover, dental care in the U.S. declined by the largest percentage among the young adult population between 18 and 24 years (Medical Expenditure Panel Survey [MEPS], Agency for Healthcare Research and Quality [AHRQ], 2011). Over the past decade, hospital Emergency Departments (EDs have seen a doubling of visits for non-traumatic dental conditions and young adults have accounted for much of this increase (Wall, Nasseh, & Vujicic, 2013). Analgesic and antibiotic prescriptions were provided 75% and 54% of the time, respectively, by ED physicians, possibly indicating a lack of time and uncertainty of oral disease diagnosis (Okunseri, Okunseri, Thorpe, Xiang & Szabo, 2012). Palliative treatment for oral pain in EDs can provide temporary relief for patients, but does not address the need for better access to dental services. Further, these treatments are expensive and do not promote the establishment of routine preventive oral healthcare (Wall et al., 2013). Table 1 demonstrates the low utilization rates of oral healthcare services for young adults ages 18-25, compared to other age groups.

Healthcare in the United States

Healthcare services sought by young adults in the U.S. with or without special health needs are commonly offered within a fragmented system of care; this is particularly true for mental health and oral health services (NRC & IOM, 2009).



Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey. (2005). *Dental Visits MEPS HC 144B.* Retrieved from meps.ahrq.gov/data_stats/download_data_files_detail.

Figure 3. Children, adolescents, and adults (2+ years) who visited the dentist in the past year by age, 2011

Table 1

Past-Year Healthcare Utilization Rates by Age Group: 2009 Medical Expenditure Panel Survey (rates adjusted for pregnancy)

	Children (aged 0-11) %	Adolescents (aged 12-17) %	**Young Adults (aged 18-25) %**	Adult (aged 26-44) %	Adult (aged 45-64) %	Adult (aged 65+) %
Utilization % had any health care utilization	88***	83***	**72**	78***	89***	97***
Office-based visits % had visit(s)	77***	67***	**55**	65***	79***	91***
Hospital outpatient visits % had visit(s)	7	5	**7**	12***	20***	30***
Emergency room visits % had visit(s)	15	12**	**15**	12**	12***	17
Inpatient hospitalizations % had visit(s)	2***	4***	**5**	6	7*	19***
Prescription medications % had prescription(s)	50	49	**48**	57***	75***	92***
Dental visits % had visit(s)	44***	53***	**34**	37	47***	44***

Source: National Research Council (NRC) and Institute of Medicine (IOM). (2014). *Investing in the health and well-being of young adults.* Washington, DC: The National Academies Press.

Notes. Hospital outpatient visits are to general clinics that are hospital-based.
***$p < 0.001$ **$p < 0.01$ *$p < 0.05$

Healthcare is accessed in various settings with gaps in insurance eligibility and little exchange of health information between providers (NCR & IOM, 2009). Young adults need support to navigate a system that is delivered in multiple settings, public and private (Tanner et al., 2013). Uninsured or underinsured adolescents often have difficulty gaining access to private office-based primary care medical or dental services and may have difficulty in finding providers to meet their acute and chronic needs (Mulye et al., 2009; NCR & IOM, 2009). Disease prevention and health promotion are frequently secondary considerations for a healthcare system focused on acute conditions such as infections, injuries, substance abuse, or contraception (NRC & IOM, 2009).

YALWH must navigate a healthcare system with a background of social and economic pressures, such as parental loss, lack of housing security, poverty, marginalization, discrimination, abuse, and stigmatization (AAP, 2013). Adolescents and young adults infected with HIV frequently present for care with histories of poor medication adherence, which can limit treatment options. It is important to address the healthcare needs of this population with considerations for confidentiality, ease of access to care, and a support staff oriented toward serving this demographic (AAP, 2013; Tanner et al., 2013).

HIV

The success of HIV antiretroviral therapies has contributed to an increased number of adolescents living with HIV in the U.S. These therapies have been instrumental in increasing the survival rates for perinatally infected youth and those infected through adult sexual risk behaviors (AAP, 2013). Young adults represent

approximately 50% of all HIV infections across the globe (Kaiser Family Foundation, 2012). In the U.S., approximately 39% of all new HIV infections occur in adolescent and young adult populations 13 to 29 years of age, and HIV is the seventh leading cause of death in this age group (AAP, 2013; Kaiser Family Foundation, 2012). Additionally, in 2010 it was estimated that 59.9% of 13- to 24-year-olds with HIV were unaware of their HIV infection (Hyden, Allegrante, & Cohall, 2013; Rao et al., 2007). Difficulties with medication adherence often result in increases in viral loads as well as increased risk of transmission, which is a public health concern affecting efforts to eradicate this disease (Tanney et al., 2010).

Disparities in HIV prevalence among young adults continue to persist. Among African-American men who have sex with men (MSM), for example, the largest new HIV diagnoses have occurred among the 13-24 year olds. Further, it was recently estimated that 77,000 newly infected individuals were in this age group (AAP, 2013). The proportion of young adults aged 13-24 years with a suppressed viral load is 25.4%, compared to 38.1% in older adults living with HIV. Additionally, the proportion of adolescents regularly testing for HIV is lower (74.6%) in comparison to the 87.8% of adults who report regular testing for HIV (Mahle Gray et al., 2013).

Health Literacy

Health literacy is defined as the ability to obtain, process, and understand basic health information and services to improve one's ability to better make health choices (Manganello, 2007). Research in 2006 and 2007 found that adolescents frequently read below grade level and, although interested in learning more about health, have difficulty

understanding information provided by healthcare professionals (Brown, Teufel, & Birch, 2007; Davis et al., 2006). Patients with chronic illnesses with higher health literacies have been found to exhibit the greatest understanding of information and are more likely to adhere to instructions for medication schedules and follow-up visits (Gong et al., 2007). Conversely, patients found to have low literacy skills are more likely to have a poor working knowledge of HIV (Wolf et al., 2006). Health literacy for adolescents and young adults living with HIV is increasingly important as more patients in this age group become self-reliant for their health and healthcare services (Osborn, Paasche-Orlow, Davis, & Wolf, 2007).

HIV Stigma

YALWH live with a potential sequella of associated illnesses such as dyslipidemia, growth failure, respiratory illnesses, increased risk of cardiovascular disease, and oral heath diseases, frequently with a backdrop of depression, marginalization, and stigmatization (Foster et al., 2007; Gardner, McLees, Steiner, Del Rio, & Burman, 2011). Those vertically infected from a parent may be dealing with sadness due to the loss of parents and friends from AIDS, as well as hostility towards parents who have infected them (AAP, 2013; Foster et al., 2007). YALWH identifying as LGBTQ often face a life of additional discrimination that can impact, for example, employment abilities that typically result in housing insecurity and homelessness (AAP, 2013). Indeed, it has been estimated that LGBTQ youth represent 40% of the homeless youth population in the United States (Seybolt, 2013). Further, surveillance data have shown that MSM have remained a core population at particular risk for being infected

with HIV and continue to be victims of HIV stigma discrimination (Beyer et al., 2012). Stigmatization from peers, family members, and friends as well as healthcare providers have social and health implications, such as isolation and low medication adherence (Dowshen et al., 2009).

Stigma concerns are widespread among people with HIV. Being rejected and fearing rejection are often reported concerns of individuals living with HIV/AIDS (Beger, Estwing Ferrans, & Lashley, 2001). The literature has reported that disclosing HIV status is met with mixed results for many living with this virus. Responses range from acceptance to negative social identity resulting in social distancing, as well as HIV becoming a defining trait (Berger et al., 2001). Handling the emotional after-effects of stigma takes energy and each new disclosure raises the fear of potential rejection (Donohue, 1991). This fear of rejection may make young adults less willing to be tested and thus increases the need to establish a medical and dental home so that repeated disclosure is not required (Lehrer et al., 2007; Reznik, 2012; Yu et al., 2001).

Stigma as it relates to HIV can be attributed to a variety of health delivery concerns such as disclosure reluctance, negative self- image, sensitivity regarding public attitudes, and personalized stigma (Dowshen et al., 2009). Social disadvantages caused by HIV stigma can result in increased stress for infected young adults and can impact health outcomes as do other social determinants such as socioeconomic status (SES) or racial discrimination (Hatzenbuehler et al., 2013). Negative attitudes towards people living with HIV despite legislation and education persist within the LGBTQ community as well as the general population, and have been associated with poor health and poor

medication adherence for all age groups (Dowshen et al., 2009; Hatzenbuehler, 2011). Adolescents and young adults have reported skipping medication doses due to fear that friends or family will discover their status or discriminate against them (Rao et al., 2007).

Oral Health and HIV

Oral health contributes to one's quality of life and is particularly important for PLWHA because they are disproportionally affected by oral diseases such as dental caries (decay) and periodontal disease (gum disease) (Freed et al., 2005; Mofidi & Gambrell, 2009). Good oral health also allows a person to speak, smile, chew, and feel socially accepted - all important issues for young adults who are developmentally more sensitive to peer opinions (Mofidi & Gambrell, 2009).

Living with the burden of oral infection can jeopardize the general health of medically compromised patients (Cherry-Peppers, Daniels, Meeks, Sanders, & Reznik, 2003; Hodgson, Greenspan, & Greenspan, 2006; Liberali et al., 2013). Poor oral health can result in difficulty chewing, which can impact patients' willingness to adhere to nutrition and medication regimens, further damaging the immune system and leaving individuals susceptible to a sequella of opportunistic infections (Mofidi & Gambrell, 2009; Tobias, Lemay, Jeanty, Umez-Eronini & Reznik, 2012).

Oral manifestations of HIV are often an indication of the progression of the viral infection and can occur in approximately 30-80% of PLWHA (Cherry-Peppers et al., 2003). The mouth is often the first to demonstrate the presence of HIV through lesions and fungal conditions. Preventive dental care including regular examinations may lead to the detection of HIV before a patient is aware he/she is infected and may be the most

low-cost mechanism for diagnosing and tracking HIV (Ramos-Gomez & Folayan, 2013; Tobias, Fox et al., 2012). Further, research has suggested that patients receiving oral health education were more likely to remain in oral healthcare (Tobias, Fox et al. 2012).

HIV-related oral opportunistic infections have been related to a suppressed immune system (John, Stephen, & Africa, 2013; Reznik, 2005; Tami-Maury et al., 2011; Vernon et al., 2009). The occurrence of opportunistic infections such as Kaposi sarcoma and oral leukoplakia have decreased since the development of HAART. We still see, however, the prevalence of conditions such as orapharyngeal candidiasis, major apothous ulcers, HIV salivary gland disease, HIV-related Human Papillomavirus (HPV), head and neck cancers, and oral warts (Beachler & De Souza, 2013; Patton, 2013).

HIV also increases the risk for periodontitis, an infection that can lead to tooth loss and oral discomfort (Ryder, Nittayananta, Coogan, Greenspan, & Greenspan, 2012). Research has suggested that CD4 cell levels less than 200cells/mm can increase the risk for periodontal disease twice that of cigarette smoking (Vernon et al., 2009). Periodontal disease is an inflammatory condition with risk factors that include smoking and inadequate oral hygiene, in addition to HIV status (John et al., 2013). Smoking is a risk behavior frequently seen in YALWH (Neinstein, 2013; Park et al., 2006). Major apthous ulcers are very painful and can make eating some foods difficult. Xerostomia or dry mouth as a result of medication regimens or salivary gland enlargement increases the risk of dental decay (Reznik, 2005; Tami-Maury et al., 2011).

HPV is commonly associated with cervical cancer, but research has established it as significantly associated with head and neck cancers. The risk associated with HIV-associated HPV has been found to be independently correlated with sexual behavior,

including lifetime number of sexual partners (Beachler & De Souza, 2013). Head and neck cancers in the oral cavity and larynx from HPV not related to HIV have been found to be associated with tobacco and alcohol use behaviors frequently seen in young adult populations (Beachler & De Souza).

Dental Fear

Dental fear resulting in the exacerbation of oral diseases has been identified as a "cycle of dental fear" for populations not already dealing with the burden of HIV/AIDS (Armfield et al., 2007). However, avoidance of dental care has been reported as three times higher for PLWHA (Patton et al., 2013). Singer and colleagues (2012) reported patients in an HIV clinic with high levels of dental fear had a 69% lower adjusted-odds ratio of using available dental services than patients with lower levels of dental fear. Dental fear and anxiety have been documented as factors in increasing the caries rate of morbidity and the need for greater dental rehabilitation services (Eitner, Wichmann, Paulsen, & Holst, 2006). Ng, Chau, and Leung (2004) found that providing patients with pretreatment information on dental procedures reduced patients' level of fear

Access to Oral Health Services

Access to oral healthcare is a frequently reported disparity for PLWHA (Fox et al., 2012; Rajabiun et al., 2012). A recent report on annual dental visits for the general population in the U.S. noted a reduction over the last decade in dental visits for young adults beginning age 18 years, who have the lowest utilization rates of any age group in the U.S. (Vujicic, Yarbrough, & Nasseh, 2014). Research has shown that oral health is the kind of specialized service that poor minority youth typically access through

emergency departments and receiving palliative care, thus often leaving the underlying oral health disease unresolved (Okunseri et al., 2012; Wall & Nasseh, 2013). Financial barriers and lack of dental insurance have been identified as barriers to oral healthcare for PLWHA, along with other factors such as availability of providers, dental fear, stigma, and low oral health literacy (Tobias, Lemay et al., 2012). Okunseri et al. reported a higher percentage of dental visits among respondents with parents who have a college education. This same work found that Black and Hispanic respondents were less likely to report dental examinations, with Black participants reporting fewer dental exams as adolescents or young adults (Okunseri et al., 2012).

Research has also shown that receipt of dental care from a regular provider is associated with reduced caries rates, improved periodontal health, and increased retention of existing teeth. However, it has also been shown that adolescents living in high-poverty neighborhoods have higher rates of decay and tooth loss than those in higher-income areas (Atkins et al., 2012; Tobias, Lemay et al., 2012). Numerous studies have shown that adolescents do not utilize oral health services even when offered for free or even if they have insurance, and older adolescents are less likely than younger adolescents to receive care (Atkins et al., 2012; Lehrer, Pantell, Tebb, & Shafer, 2007; Mitchell et al., 2003; Yu et al., 2001).

In 2009, the Committee on Adolescent Health reported a lack of health providers, educators, and researchers for adolescent healthcare, as well as inadequate standards for training program accreditation (NCR & IOM, 2009). Pediatric dental residency program accreditation guidelines include infants, children, and adolescent age groups in their proficiency requirements; however, most clinical experiences are related to young

children and children up to age 12 years (Commission on Dental Accreditation, ADA, Pediatric Dentistry, 2007a, 2007b). This may be due primarily to limited time and resources needed to address the well-established crisis in early childhood caries (ECC)—a chronic oral disease highly prevalent in poor minority children (AAP, 2013; Cassamassimo, Thikkurissy, Edelstein, & Maiorini, 2009; Fisher-Owens et al., 2012). Advanced General Dentistry residency program accreditation guidelines include training to provide care for a wide range of special needs populations such as those with complex medical histories, but do not cite the inclusion of adolescents or young adults living with HIV (ADA, Commission on Dental Accreditation, 2007a, 2007b).

Important predictors of healthcare utilization among YALWH include HIV stigma sensitivity, HIV status disclosure, depressive symptoms, and concrete rather than abstract reasoning skills (Hatzenbuehler, 2011; Rao et al., 2007; Yu et al., 2001). Ramos-Gomez and Folayan (2013) suggested that medical and dental health practitioners should incorporate a child-specific oral health protocol into their practices. The Ryan White Program has supported research on oral healthcare for PLWHA through the Special Projects of National Significance (SPNS), which has resulted in multiple reports on oral healthcare and adults living with HIV/AIDS including reports on: dental care-seeking behaviors, retention in oral healthcare settings, access to oral healthcare for low-income adults, increasing access to oral healthcare, a typology for expanding access to oral healthcare, methamphetamine use and dental care, and patient perspectives on improving oral healthcare delivery (Bachman et al., 2012; Fox et al., 2012; Rajabiun, Bachman, Fox, Tobias, & Bednarsh, 2011; Rajabiun et al., 2012; Tobias, Fox et al., 2012; Tobias, Lemay et al., 2012; Walter et al., 2012). Important influences that shape the utilization of

preventive oral health and medical services for adolescents and young adults have been reported, including health insurance, level of self and parental education, neighborhood poverty, dental anxiety, race/ethnicity, and availability of usual source of care in a youth friendly environment (Atkins et al., 2012; Mitchell et al., 2003; Mulye et al., 2009; Okunseri, 2013; Park et al., 2006; Yu et al., 2001). However, utilization of dental health services for YALWH has not been well documented.

Chapter III

METHODS

This research fills a gap in the present literature by studying facilitators and barriers to oral healthcare services among a sample of YALWH and members of their oral healthcare provider team.

Study Design

This mixed-methods cross-sectional study includes the collection of data via the following methods: a) an in-person quantitative survey and a semi-structured qualitative interview of young adults between the ages of 17 and 25 years living with HIV; b) an online and in-person survey of advanced general dentistry residents (AEGD), pediatric dental residents, general and pediatric dentists, and dental hygienists; and c) a focus group conducted with dental clinic support staff of a hospital-based dental clinic.

Sample Description

The sample of YALWH included in this study is comprised of 70 HIV positive participants ranging in age from 17-25 years of age (mean age = 23.0 years (SD: 2.3 years)). The majority of the sample is male (74.3%). Approximately half the participants (52.8%) are of Black/African American race and 22.9% of the participants are Hispanic.

The sample of 100 oral health professionals included in this study is comprised of general practice dentists, general practice residents, pediatric dentists, pediatric dental residents and dental hygienists. The majority of this sample (77%) is female and approximately 65% are white. Approximately a quarter of the sample (26%) are general dentists, 20% are pediatric dentists, and 54% are dental hygienists. The sample of dental staff is comprised of 6 participants, with the majority being female (83%). Approximately 66% of the participating dental staff are Hispanic and 67% of the participants reported that English is their primary language spoken with friends and family..

Setting

YALWH participants were recruited at a comprehensive health clinic for adolescents living with HIV located in a hospital center in Northern Manhattan and affiliated with New York Presbyterian Hospital. This clinic currently serves 100 YALWH.

The dentists and dental residents were recruited from Columbia University, College of Dental Medicine (CDM) alumni and dental residencies. Dental hygienists were recruited from the Dental Hygienist's Association of the State of New York (DHSANY) membership directory. The dental support staff was recruited from the hospital based dental clinic affiliated with CDM.

Qualitative Research Framework

It should be noted that for the qualitative component of this study, the pragmatic qualitative interpretive framework paradigm was used. This perspective focuses on the problem being studied rather than on the research methodology; both qualitative and

quantitative data collection and analysis methods are often embraced by this paradigm. Pragmatism posits that knowledge arises from the understanding of situations and their consequences (Bloomberg & Volpe, 2012, p. 29; Creswell, 2013, p. 28).

More specifically, this study's qualitative data collection processed utilized the phenomenological method. Although structured interviews and focus groups are often associated with case study methods, this research was not limited to a single case nor bound by time and place (Creswell, 2013, p. 97). The phenomenological method is a descriptive and interpretive process through which individual participant experiences are used to provide an understanding of a universal experience of a phenomenon (Bloomberg & Volpe, 2012, pp. 32-33). The phenomenon examined was the oral health experiences of the participants, as young children and young adults, with their parents or caregivers and dental professionals. Research inferences were made with this method from first-person reports of life experiences (Moustakas, 1994, p. 84). The researcher aimed to set aside prejudgments and preconceived ideas; a process that has been referred to as *Epoche*. The events being examined were bracketed outside the researcher's previous knowledge and thoughts to allow the phenomena to be viewed as they appeared and not clouded by the researcher's thoughts or knowledge (Moustakas, 1994, p. 85).

Researcher Experience: Implications for Qualitative Interview Data

The researcher's oral health education and clinical experiences as a dental hygienist have led to an interest in working with and studying young adult populations. In conjunction with evidence provided in the literature on YALWH, the researcher's experiences shaped techniques employed in the provision of health information for

patients at this clinic and used in this study during the qualitative semi-structured interviews. Specifically, the use of Motivational Interviewing principles (behavior change talk, change in decisional balance of behavior) and constructs from health behavior theories such as the Transtheoretical Model (stages of change) and Social Cognitive Theory (self-efficacy and expectancies) improved the researcher's ability to generate productive patient accounts of health concerns (Bandura, 1986; Prochaska & DiClemente, 1982; Rollnick, Miller, & Butler, 2008). These approaches supported the researcher's effort to maintain Epoche and allow discussions to be focused on study participants' experiences, not the researcher's reality of oral healthcare for young adults (Moustakas, 1994, p. 33).

Instruments

YALWH Patient Survey

The in-person quantitative survey items administered to the sample of YALWH (N = 70) assessed oral health behaviors, the utilization of oral healthcare services, demographic characteristics, social factors, personal belief factors, and satisfaction with dental care provided. Survey questions had a multiple-choice response format with some items comprised of Likert-type scales. This survey was adapted from multiple oral healthcare surveys including: the Health Resources and Services Administration HIV/AIDS Bureau's Special Projects of National Significance Innovations in Oral Health Care (SPNS) Survey (Fox et al., 2012), and an abbreviated HIV stigma sensitivity index developed by Wright, Naar-King, Lam, Templin, and Frey (2007) from a 40-item

questionnaire developed by Berger and colleagues (2001). The abbreviated 10-item HIV stigma questionnaire included four subscales: a) personalized stigma (consequences of other people knowing their status); b) disclosure concerns; c) negative self- image (not as good as others, feelings of guilt or shame); and d) public attitudes (what people think about people living with HIV). Previous research established the reliability and validity of this instrument. Specifically, the abbreviated scale had an internal consistency of α = .86. Cronbach's alpha analysis for each subscale with the longer version were equally as strong: personalized stigma α =.75, disclosure α =.73, negative self-image α = .84 and public attitudes α = .72 (Beger et al., 2001; Wright et al., 2007). This work also computed coefficient alphas on the original scales' identical four subscales with a sample of 318 participants: α = .93, α = .93, α = .91, α = .93. Test-retest correlations for temporal stability were performed and supported the stability of the overall instrument and subscales. Additional items used in the present dissertation were adapted from the Kleinknecht & Bernstein's Dental Fear Scale; and the Consumer Assessment of Healthcare Providers and Systems. The DFS was found highly reliable (Cronbach's alpha > 0.90) (CAHPS) survey (Agency for Healthcare Research and Quality [AHRQ], 2005; Kleinknecht & Bernstein, 1978) (see Appendix A for a copy of the complete YALWH patient survey used in this dissertation).

Oral Health Professional Surveys

The quantitative survey items administered to the sample of oral health professionals assessed HIV knowledge, perceived ability to provide culturally competent care, and perceived barriers to oral healthcare for YALWH. The survey was adapted from

the Knowledge, Efficacy, and Practices Instrument for Oral Health Providers (KEPI-OHP) developed by Behar-Horenstein et al. (2013). The KEPI-OHP had acceptable internal consistency reliability ($\alpha = .87$) and the confirmatory factor analysis fit indices indicated a strong fit for the full scale. (Behar-Horenstein et al., 2012). Survey questions had a multiple-choice response format, with some items comprised of a Likert-type scale.

Semi-Structured Interview Guides

The semi-structured interviews were intended for the sample of YALWH patients to share additional information about their oral health history since childhood, their current oral health behaviors, and details on their present support systems for medical needs (for example, support for appointment scheduling and medication management). The interview guides were developed from the Special Projects of National Significance (SPNS) Innovations in Oral Health Care patient interviews and surveys and guided by aspects of the present study's aims applicable to YALWH (Fox et al., 2012) (see Table 2). Each patient was guided by the researcher to discuss these aforementioned constructs, but was also encouraged to offer details on issues that were of particular concern to them. This was to provide the opportunity for the comprehensive disclosure of each patient's experience with oral health and oral healthcare (Moustakas, 1994, pp. 44, 123). The semi-structured interviews were intended to gather contextual information from study participants that was not necessarily included or captured by the quantitative survey items.

Table 2

Interview Questions/Research Aims Matrix

Qualitative Semi-structured Interview Questions	Components of Relevant Study Aims			
	A	**B**	**C**	**D**
1. Is oral health importance to you now?	**X**			
2. Was oral health important to your family growing up?	**X**			
3. Did your parents teach you how to brush?	**X**	**X**		
4. Did a dentist show you how to take care of your mouth, teeth, and gums?	**X**	**X**		
5. Have you had positive dental experiences?	**X**			
6. Have you had negative dental experiences?			**X**	**X**
7. Do you have support systems for healthcare?			**X**	**X**
8. What are your oral health habits?	**X**	**X**		
9. How could oral health services be improved?			**X**	**X**

A. What is the perceived value of oral health care services and behaviors among YALWH?

B What are the daily oral health behaviors, social, and personal health belief factors associated with normative utilization of oral healthcare among YALWH?

C. What are perceived barriers to oral healthcare among YALWH?

D. What are facilitators and barriers associated with normative utilization of oral healthcare among YALWH?

Focus Group Items

Dental support staff interview guides were developed from items included on the YALWH patient and oral health professional survey items and guided by aspects of the present study's aims applicable to dental support staff (see Table 3). The researcher utilized this focus group to gather data on the staff's perceived role in dental clinic

services for YALWH as well as their perceived barriers and facilitators to providing oral healthcare services.

Table 3

Focus Group Questions/Study Aims Matrix

Focus Group Questions	Components of Relevant Study Aims		
	A	**B**	**C**
1. Describe importance of your interactions with patients in your clinic.	**X**		
2. Do you feel you play a key role when working with YALWH?	**X**		
3. Do you think everyone that is HIV+ reports their status?		**X**	
4. Are YALWH difficult to provide care for?		**X**	
5. What can members of the dental clinic staff do to help YALWH keep their appointments?	**X**	**X**	
6. What can members of the dental clinic staff do to help YALWH feel welcome at the clinic?	**X**		**X**
7. Are YALWH fearful of seeing the dentist?		**X**	
8. Do you feel you receive appropriate training to work with YALWH?			**X**
9. If you could change anything about the care your clinic offers YALWH what would that be?			**X**

A. What is the role of dental staff in providing care to YALWH?
B. What are barriers associated with utilization of oral healthcare by YALWH as perceived by dental staff?
C. What are facilitators associated with utilization of oral healthcare by YALWH as perceived by dental staff?

Recruitment

YALWH Patient Recruitment

YALWH participants were recruited from an adolescent HIV/AIDS comprehensive care center in northern Manhattan. Inclusion criteria were patients with an HIV+ diagnosis between ages 17 and 25 years enrolled as patients at the HIV comprehensive medical clinic located in northern Manhattan. It should be noted that a team of physicians, nurse practitioners, psychiatrists, and social workers together provide care for 100 YALWH at this particular clinic. The location of a dental clinic in the same building that these youth receive medical care increased accessibility to patients who may have had a recent dental experience to discuss during the study's data collection process.

Participants were recruited using convenience and snowball sampling methods at the time of a medical visit. Recruitment was initiated by a member of the clinic provider team and completed by the researcher to ensure patients comfort in refusing to participate. Prospective participants were informed by the researcher of the voluntary nature of their participation, the lack of any personal risks or consequences, and their right to refuse to participate at any time during the study. Participants were then asked to sign a consent agreement. A waiver of parental consent was granted by the Internal Review Boards at Columbia University Medical Center (CUMC) and Columbia University, Teachers College, as some of the clinic patients younger than 18 did not have access to parent(s) to obtain consent. However, whenever possible, participants under the age of 18 were asked to obtain the consent of a parent or consenting adult. No personal identifiable information was collected or stored.

Oral Health Provider and Clinic Staff Recruitment

Oral health providers were recruited through the CDM alumni email list, the AEGD and pediatric dentistry (PDR) residency programs, and the Dental Hygienists Association of the State of New York (DHASNY). Support staff of the hospital-based dental clinic located in northern Manhattan were asked by the clinic director to participate in a focus group. Staff members included dental assistants, registration desk personnel, and call-in center personnel.

Participant Incentives

YALWH patient participants were provided a $5.00 coffee gift card and an oral health travel pouch containing a toothbrush, toothpaste, fluoride mouth rinse, dental floss, and sugar-free gum or mints. Dental professional participants were furnished with a $5.00 coffee gift card. Dental clinic staff focus group participants were provided refreshments and a $5.00 coffee gift card as a token of the researcher's appreciation of their time. All incentives were approved by the aforementioned IRBs.

Data Collection

Quantitative Data

YALWH patient participants were asked to complete the in-person quantitative survey that was read aloud by the researcher. The interviewees selected the answers that best described their experiences.

Quantitative data were simultaneously collected from a sample of oral health professionals. To accommodate the participants' needs, this survey was administered to

one subset of the sample in-person (via paper/pencil) and to another subset of the sample online. Specifically, in-person survey instruments were provided for the AEGD and PDR residents, before and after didactic course meetings (to reach as many residents as possible), with the permission of program directors. Pediatric dentistry and general dentistry CDM alumni were emailed a study information letter that contained a link to the online survey supported by Qualtric online survey solutions system. Dental hygienists were provided with an in-person survey at local component continuing education meetings of the Dental Hygienists Association of the State of New York (DHASNY), with permission of the component board of directors. The researcher also posted the study's information with the link to the online survey in a DHASNY newsletter (see Appendix E for sample Professional Survey and study information letter).

Qualitative Data

YALWH patient semi-structured interviews were conducted after their completion of the quantitative survey. Upon completion of the quantitative survey, if the participants agreed, they participated in a qualitative semi-structured interview. This interview consisted of nine open-ended questions regarding patients' oral health and their social support network. The length of the survey and interview was approximately one hour. All interviews were recorded on an MP3 audio recording device and subsequently transcribed following the interview to ensure accuracy during analysis. Interviews provided an opportunity to collect additional information about the participants' oral health experiences. It should be noted that these qualitative data were not intended to validate information collected on the quantitative surveys, rather to provide additional

context for their experiences with oral healthcare (see Appendix B for sample of patient structure interview questions).

The focus group was conducted with dental clinic staff to gather data on the staff's perceived role in dental clinic services for YALWH, as well as to identify their barriers and facilitators for implementing comprehensive oral healthcare services among vulnerable populations. The focus group was recorded on an MP3 audio recording device with the permission of all participants. No personal identifiable information was recorded and each participant was instructed to use only first names. Participants were provided with background information about the study and the voluntary nature of their participation. After all participants' questions were answered and they expressed interest in participating, they were asked to complete an informed consent form. A six-item demographic survey was also completed by each focus group participant (see Appendix D for a sample Dental Clinic Staff Focus Group Guide and Demographic Survey).

Data Management

Quantitative Data

All quantitative data were entered into the Qualtrics survey software program and then exported into the Microsoft Excel data management software to check for data entry accuracy. Changes were made where necessary. All data were then imported into SPSS (version 21). Missing values were assigned a code of 99. String variables were coded as individual variables and dichotomized as "zeros" and "ones" where appropriate. Dichotomous multiple-choice items were also were coded as "0" and "1," with 0 equaling "no" or "never" and 1 equaling "yes" or "ever" engaging in a specific behavior.

Qualitative Data

The framework data analysis approach was used for all qualitative data. This approach is well suited for cross-sectional descriptive data as it allows for a detailed analysis of the phenomenon under consideration (Smith & Firth, 2011). Patient interviews and focus group transcripts were read and re-read several times to ensure the researcher's understanding of the data. The researcher's field notes were also reviewed several times to remind her of settings and individual patient life events that might influence their responses. Key words and themes were noted and used to inform the interpretation and synthesis of the qualitative data (also see Data Analysis section for more details).

Data Analysis

Frequencies and descriptive statistics were utilized to describe key variables from the YALWH patient surveys, oral healthcare professional survey, and dental staff demographic survey. The distribution of key variables for young adult participants and oral health professionals were computed, including: age, gender, race/ethnicity, specific type of oral health professional (pediatric dentists, general dentist, and dental hygienists), cultural competency, HIV knowledge, and perceived barriers to care.

Aim 1

Frequencies were utilized to describe: a) the distribution of oral health-related behaviors among the study's sample of YALWH (tooth brushing, flossing, fluoride rinse,

sugar-sweetened snacks and soda, tobacco use), and b) perceived barriers to care (dental insurance, appointment time, not important, could not afford it).

Semi-structured interview qualitative analysis.

Salient statements made during the semi-structured qualitative interviews were highlighted on the transcripts and used to create a list of themes. These themes were clustered and codes were developed following the study's conceptual framework. The researcher then re-read the transcripts to check that codes reflected the original data. Each code was assigned to a category that aligned with the study aims. Codes used were: a) importance of oral health, b) oral health-related behaviors, c) oral health-related concerns, d) negative dental experiences, e) positive dental experiences, and f) support systems of patients. Based on the frequency of specific responses, these codes were then collapsed into four categories corresponding with dissertation study's Aims 1 and 2: a) value of oral health, b) daily oral health behaviors, c) barriers to oral healthcare service, and d) social, personal, and health belief factors (see Table 4).

Table 4

Qualitative Interview Coding Legend

Category	Codes	Themes
Value of Oral Health	▪ Importance of Oral Health ▪ Oral Health Behaviors	▪ Oral Health is Important ▪ Does not receive regular dental care
Daily Oral Behavior	▪ Oral Health Behaviors ▪ Oral Health Behaviors	▪ Brushing only ▪ Brushing, Flossing and Use of Mouth Rinse
Barriers to Oral Healthcare	▪ Negative Dental Experiences	▪ Poor Dental Professional Skills

	▪ Oral Health Related Concerns ▪ Oral Health Related Concerns ▪ Negative Dental Experience	▪ Fear of Tooth Loss ▪ Medicaid Insurance limitation of Dental Services ▪ Fear of Dental Clinical Therapies
Social, Personal and Health Belief Factors	▪ Support System of Patients ▪ Oral Health Related Concerns ▪ Positive Dental Experience ▪ Support System of Patients	▪ Support Self Reliant for Medication and Appointment Management ▪ Bleeding Gums, Appearance, Clean Teeth ▪ Compassionate Dental Providers ▪ Mom provided tooth brushing instruction as child

Aim 2

Using data collected from the YALWH quantitative surveys, cross-tabulation tables to compare frequencies and Pearson Chi Square to tests for differences between the following set of variables were conducted: social factors (transportation, food security, employment status, education, home condition, and insurance); personal beliefs (self-perceived oral health status, HIV stigma sensitivity and dental fear); and the normative care variables: (dental visit within last 12 months and dental home or regular place to receive oral healthcare).

Aim 3a

Data from the oral health professional surveys were used to create mean scores for cultural competency across all participants and for each question (calculated on a scale ranging from 1-4 points for each item). Professions were subsequently ranked by question with 1 = the highest and 3 = the lowest using Kruskal-Wallis test. The Kruskal-

Wallis test was also used to compute the mean overall rank for all 28 cultural competency questions.

Aim 3b

HIV knowledge mean scores were computed (scale range: 1-3) and compared across professional group using the Kruskal Wallis non-parametric test.

Aim 3c

Perceived barriers to care were similarly ranked by frequency and comparisons were made within and between each oral health profession. The Kruskal Wallis test was used in this portion of analyses because the number of participants per professional group was uneven, thus meeting the criteria for a non-parametric analysis.

Aim 4

Dental clinic support staff focus group analyses followed a similar qualitative framework analysis as the semi-structured interview analyses described in Aim 1. Salient statements were highlighted within the focus group transcripts and used to create a list of themes. These themes were clustered and codes were developed following the study's conceptual framework. The researcher then re-read the transcripts to check that codes reflected the original data. Each code was assigned to a category that aligned with the study aims.

Chapter IV

RESULTS

The results corresponding to Aims 1-4 are presented in detail in this chapter. Quantitative data from 70 YALWH participants and 100 oral health professional participants are presented. Qualitative data from 26 YALWH participants and six dental staff participants are presented.

Frequency Distribution of Key Demographic Variables

The frequency distribution of key demographic variables for both the YALWH participants and oral health professional participants were computed. The results are presented below in Tables 5, 6, and 7.

Table 5

Young Adult Demographic Variables (N = 70)

Variable	Mean	SD
Mean Age (years)	23.0	2.3
	N	**%**
Gender		
Male	52	74.3
Female	15	21.4
Transgender	3	4.3
Ethnicity		
Black/African American	37	52.8
White Non-Hispanic	1	1.4
Hispanic	16	22.9
Multiracial	10	14.3
Other	6	8.6

Table 6

Professional Demographic Variables (N = 100)

Variables		N	%
Gender			
	Male	22	22.9
	Female	74	77.1
Race/Ethnicity			
	Black	1	0.9
	Asian	14	13.1
	White	69	64.5
	Hispanic	15	14.0
	Multiracial	8	7.5
Profession			
	General Dentist	26	26.0
	Pediatric Dentist	20	20.0
	Dental Hygienist	54	54.0

Table 7

Dental Staff Demographic Variables (N = 6)

Variables		N	%
Gender			
	Male	1	16.7
	Female	5	83.3
Race/Ethnicity			
	Black	1	16.6
	Hispanic	4	66.6
	Other	1	16.7
Education			
	College	5	83.3
	Elementary-High School	1	16.7
Language Spoken			
	English	4	67.7
	Spanish	2	33.3
Employment			
	Full Time	6	100.0
Transportation			
	Car	1	16.7
	Bus	2	33.3
	Subway	3	50.0

Aim1a Results: Oral Health-Related Behaviors

A description of the YALWH oral health related behaviors was completed utilizing a frequency distribution and the results are presented in Table 8 below. The majority of study participants reported healthy daily oral health behaviors and low utilization of tobacco products. However, consumption of sugar-sweetened beverages and candy were both frequently reported among this sample.

Table 8

Aim 1a: Oral Health Behaviors (N = 70)

Behaviors		N	Percent
Brush Daily			
	Yes	65	92.9
	No	5	7.1
Floss			
	Yes	37	52.9
	No	32	45.7
	Don't Know	1	1.4
Fluoride Rinse			
	Yes	39	57.4
	No	29	42.6
Drink Sugar-sweetened Soda			
	Yes	55	78.6
	No	15	21.4
Sugar-sweetened Candy and Gum			
	Yes	56	80.0
	No	14	20.0
Smoke Cigarettes			
	Yes	21	30.0
	No	49	70.0
Smoke Hookah			
	Yes	20	28.6
	No	50	71.4

Aim 1b Results: Perceived Barriers to Care

Frequencies were used to describe the percentage of YALWH who identified each of the following items (presented in Table 9) as a perceived barrier to oral healthcare. The lack of insurance and ability to afford dental care were the two most frequently reported barriers to care. Data from the semi-structured interviews conducted with

YALWH indicated that poor dental professional skills were also a perceived barrier to care (please also see Table 11 in the Aim 2 results).

Table 9

Aim 1b: YALWH Patients' Perceived Barriers to Care (N = 35)

Rank	Q. No.	Question	N	Percent
1	12	I had no insurance	13	36.4
2	1	I could not afford it	10	27.3
3	5	I could not get an appointment at a time I could make it	10	27.3
4	10	I did not want to go to the dentist	10	27.3
5	3	I did not know where to find dental care	9	24.2
6	6	I did not think it was important	9	24.2
7	4	I did not have transportation	6	18.2
8	17	Other responsibilities were more important	6	18.2
9	9	I was afraid of finding out something was wrong	5	15.2
10	16	Fear of the dentist	5	15.2
11	18	Other responsibilities	5	15.2
12	7	I was worried about my privacy	3	12.1
13	11	Family responsibilities were more important	3	12.1
14	15	I had a previous bad experience	3	12.1
15	8	I did not feel well enough to go to a dentist	2	6.1
16	2	I couldn't find an HIV-friendly dentist	1	3.0
17	13	I was in prison	0	0.0
18	14	I was addicted	0	0.0

Aim 2 Results: Identify and Describe Social and Personal Health Beliefs

Cross-tabulation tables to compare frequencies and Pearson Chi-square tests to test for significant differences between normative oral healthcare utilization and social and personal belief factors were conducted. Qualitative analysis methods were used to provide descriptive results of semi-structured interviews. The results of these analyses are

presented in Tables 10 and 11. Education was a social factor that was found to have a significant association with normative care, specifically with a patient having a regular place to receive dental care ("dental home") ($\chi^2 = 7.154$, $p < .05$). . Though not statistically significant, notable differences in frequency were observed with housing security, personalized stigma sensitivity and having a dental home. The overall mean HIV stigma sensitivity score was 2.9 (SD = 0.7); the mean score for the subcategories were: disclosure sensitivity 3.9 (SD = 1.1), public attitude 3.5 (SD = 1.2), negative self-image 1.9 (SD = 1.0) and personalized stigma 2.4 (SD = 1.0).

Table 10

Aim 2: Social and Personal Belief Factors and Normative Utilization (N = 70)

Factors and Beliefs	Normative Utilization					
	Dental Home			Visit within last 12 months		
	Yes n (%)	No n (%)	Chi-Square p-value	Yes n (%)	No n (%)	Chi-Square p-value
Social Factors						
Transportation						
Bus or Subway	25 (62.5)	19 (63.3)	0.943	24 (61.5)	20 (64.5)	0.798
Other	15 (37.5)	11 (36.7)		15 (38.5)	11 (35.5)	
Food Security						
Had enough	27 (67.5)	17 (56.7)	0.353	27 (69.2)	17 (54.8)	0.216
Did not have enough	13 (32.5)	13 (43.3)		12 (30.8)	14 (45.2)	
Employment						
employed	17 (42.5)	11 (36.7)	0.622	18 (46.2)	10 (32.3)	0.238
unemployed	23 (57.5)	19 (63.3)		21 (53.8)	21 (67.7)	
Home Condition						
Own Home	26 (65.0)	11 (36.7)	0.063	23 (59.0)	14 (45.2)	0.215
Someone else	9 (22.5)	12 (40.0)		12 (30.8)	9 (29.0)	

Other	5 (12.5)	7 (23.3)		4 (10.3)	8 (25.8)	
Insurance Status						
Medicaid	31 (79.5)	24 (80.0)	0.958	32 (84.2)	23 (74.2)	0.303
Other	8 (57.1)	6 (20.0)		6 (15.8)	8 (25.8)	
Education						
High School	26 (65.0)	11 (36.7)	0.027*	23 (59.0)	14 (45.2)	0.514
College	5 (12.5)	3 (10.0)		4 (10.3)	4 (12.9)	
Other	9 (36.0)	16 (53.3)		12 (30.8)	13 (41.9)	
<u>Personal Beliefs</u>						
HIV Stigma						
Low Disclosure Sensitivity	24 (60.0)	13 (43.3)	0.167	20 (51.3)	17 (54.8)	0.767
High Disclosure Sensitivity	16 (40.0)	17 (56.7)		19 (48.7)	14 (45.2)	
Low Public Attitude Sensitivity	21 (52.5)	12 (40.0)	0.300	22 (56.4)	11 (35.5)	0.081
High Public Attitude Sensitivity	19 (47.5)	18 (60.0)		17 (43.6)	20 (64.5)	
Low Personalized Stigma	35 (87.5)	22 (73.3)	0.131	33 (84.6)	24 (77.4)	0.442
High Personalized Stigma	5 (12.5)	8 (26.7)		6 (15.4)	7 (22.6)	
Low Negative Self-Image	37 (92.5)	25 (83.3)	0.233	35 (89.7)	27 (87.1)	0.730
High Negative Self-Image	3 (7.5)	5 (16.7)		4 (10.3)	4 (12.9)	
Dental Fear						
Low	30 (75.0)	24 (80.0)	0.622	30 (76.9)	24 (77.4)	0.961
Medium/High	10 (25.0)	6 (20.0)		9 (23.1)	7 (22.6)	
Rating Oral Health						
Good-Fair	23 (57.5)	21 (70.0)	0.284	25 (64.1)	19 (61.3)	0.809
Excellent-Very good	17 (42.5)	9 (30.0)		14 (35.9)	12 (38.7)	

*Corresponding for those results meeting criteria at the $p < .05$ level:
Pearson Chi Square Test Statistic for significant results; Education and Dental Home $\chi^2 = 7.154$.

Table 11 presents the key themes that emerged from qualitative interviews with the YALWH participants. Quotations that correspond with each category are presented below Table 11.

Table 11

Aim 2: Qualitative YALWH Participant Interview Results (N = 26)

Category	Themes	N	%
Value of Oral Health	Oral Health is Important	23	87
	Does not receive regular dental care	14	54
Oral Health Related Behaviors	Brushing only	5	20
	Brushing, Flossing and Use of Mouth Rinse	20.5	79
Barriers to Oral Healthcare	Poor Professional Communication Skills	26	100
	Fear of Tooth Loss	9	33
	Medicaid Insurance limitation of Dental Services	26	100
	Fear of Dental Clinical Therapies	26	100
Social Support	Support Self Reliant for Medication and Appointment Management	23.6	91
Personal Health Belief	Bleeding Gums, Appearance, Clean Teeth	26	100
	Compassionate Dental Providers	19.5	75
	Mom Provided Tooth Brushing Instruction as Child	26	100

The following are exemplars of categories identified from the structured interviews:

Oral health related behaviors:

”I brush my teeth first thing in the morning then I shower. I have to fit floss in somewhere. I rinse with Listerine right after I get out of the shower.” (Structured interview quote 1).

Personal health belief:

"Yes it is important. My smile is by best accessory. Having a, the appearance of your teeth matters to me a lot" (Structured interview quote 2).

Personal health belief:

"My teeth are the reason I'm trying to quit smoking. I um everybody told me about cancer and I didn't care about cancer, and then I saw something on the computer about teeth and smoking. I was like aww great they got me where they wanted me" (Structured interview quote 3).

Social Support:

"My social workers and doctors help me. My phone is programed to remind me to take my medication. I set an alarm that says 'take your candy' so someone else is not gonna know what it is talking about" Structured interview quote 4).

Barriers to oral healthcare:

" Uh well, I wanted to get braces to like straighten out my teeth, but my Medicaid don't pay for doesn't pay for it, so you know, I'm pretty much, you know, stuck with the way my teeth look until, I get a job, you know and I can pay down on the braces that I want" (Structured interview quote 5).

Value of oral health:

"Just the little things about the dentist, always leaving with a clean mouth I remember that. I remember my teeth feeling like not dry, but they felt like brand new. Like it was just very different and I want to feel that again" (Structured interview quote 6).

Barriers to oral healthcare:

"If you applied or are accepted for like Medicaid and stuff I just think there should be a little bit more added to the benefits we get too. I just feel as though all my Medicaid can cover is a teeth cleaning and X-rays. I mean hey, it's a start and its' something but what if you need this and I can't afford it. It is like they tell you we're going to do this for you but we can't do that afterwards" (Structured interview quote 7).

"Yeah, I feel kids are way smarter so I feel though now that you know like newly diagnosed teenager young adults are getting Medicaid. I ultimately feel like it's like the ball is in their park. Other people would never even look into that Medicaid covers dental" (Structured interview quote 8).

Personal health belief: "Each time you go to the clinic there somebody different. That's the only thing I don't like. It is annoying cause each time you see a new person you have to keep on telling them your life. You have to keep on telling them that you was born with HIV so that's the only thing like there a new person each time" (Structured interview quote 9).

Barriers to oral healthcare: "They need more privacy in the waiting room, somebody is right there when I'm filling out the application, it feels crowded.(Structured interview quote 10).

Barrier to oral healthcare:

"Dental care shouldn't be just about salary. It should be about caring for patients. Sometimes you can tell they just don't care. You can tell 'cause communication happens more in body language than actually talking to somebody" (Structured interview quote 11).

Aim 2 Results: Social Factor, Personal Beliefs, and Normative Care Comparison

To ensure that the YALWH participants who also participated in the qualitative interviews were similar in their normative care and key social factors to the larger sample of YALWH participants, cross-tabulation tables to descriptively explore differences between normative oral healthcare utilization and social and personal belief factors were generated. These tables compared all YALWH survey participants (n = 70) to the subset of YALWH participants who also participated in semi-structured interviews (n = 26). Table 12 presents these frequencies (also see Appendix C for frequency distribution results for each YALWH study group). Similar frequencies were observed in both groups, with the exception of home condition and education. Fewer participants within g the sub-set sample reported having a regular place for care, visiting a dentist within the past 12 months, or having a high school education as noted in Table 12,

Table 12

Aim 2: Comparison of Quantitative and Qualitative YALWH Participants

Factors and Beliefs	Normative Utilization							
	N = 70^				N = 26^^			
	Dental Home		Visit within 12 months		Dental Home		Visit within 12 months	
	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)
Social Factors								
Transportation								
Bus or Subway	62.5	63.3	61.5	64.5	70.0	81.2	77.8	76.5
Other	37.5	36.7	38.5	35.0	30.0	18.8	22.2	23.5
Food Security								
Had enough	67.5	56.7	69.9	54.8	70.0	56.3	44.4	70.6
Did not have enough	32.5	43.3	30.8	45.2	30.0	43.7	55.6	29.4
Employment								
employed	42.5	36.7	46.2	32.3	50.0	37.5	55.6	35.3
unemployed	57.5	63.3	53.8	67.7	50.0	62.5	44.4	64.7
Home Condition								
Own Home	65.0	36.7	59.0	45.2	40.0	43.8	33.3	47.1
Someone else	22.5	40.0	30.8	29.8	30.0	31.2	55.6	17.6
Other	12.5	23.3	10.3	25.8	30.0	25.0	11.1	35.3
Insurance Status								
Medicaid	80.0	80.0	84.2	74.2	80.0	81.2	100.0	70.6
Other	20.0	20.5	15.8	25.8	20.0	18.8	0.0	29.4
Education								
High School	65.0	36.7	59.0	45.2	40.0	43.7	33.3	47.1
College	12.5	10.0	10.3	12.9	30.0	6.3	11.1	17.6
Other	22.5	53.3	30.8	41.9	30.0	50.0	55.6	35.3
Personal Beliefs								
HIV Stigma								
Low Disclosure Sensitivity	60.0	43.3	51.3	54.8	70.0	31.3	22.2	58.8
High Disclosure Sensitivity	40.0	56.7	48.7	45.2	30.0	68.7	77.8	41.2
Low Public Attitude Sensitivity	52.5	40.0	56.4	35.5	30.0	25.0	33.3	23.5
High Public Attitude Sensitivity	47.5	60.0	43.6	64.5	70.0	75.0	66.7	76.5
Low Personalized Stigma	87.5	73.3	84.6	77.4	90.0	62.5	77.8	10.6
High Personalized Stigma	12.5	26.7	15.4	22.6	10.0	37.5	22.2	29.4
Low Negative Self-Image	92.5	83.3	89.7	87.1	100.0	87.5	100.0	88.2
High Negative Self-Image	7.5	16.7	10.3	12.9	0.0	12.5	0.0	11.8

Table 12 (continued)

Factors and Beliefs	Normative Utilization							
	N = 70^				N = 26^^			
	Dental Home		Visit within 12 months		Dental Home		Visit within 12 months	
	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)
Dental Fear								
Low	75.0	80.0	76.9	77.4	90.0	93.8	100.0	88.2
Medium/High	25.0	20.0	23.1	22.6	10.0	6.2	0.0	11.8
Rating Oral Health								
Good-Fair	64.7	57.9	64.1	61.3	70.0	56.3	88.9	47.1
Excellent-Very good	35.3	42.1	35.9	38.7	30.0	43.7	11.1	52.9

^ All YALWH participants (n = 70)
^^ YALWH participants who also participated in semi-structured interviews (n = 26).

Dental fear. Cross-tabulation tables were also used to descriptively compare frequencies in normative care with dental fear scores among the sample of YALWH. Specifically, a comparison of specific dental fear topics was conducted. The results of the most frequently cited dental fear topics for YALWH with low (n = 54) and medium/high (n = 16) levels of dental fear are presented in Table 13. Study participants, regardless of their level of dental fear, reported fears relating to dental instruments and procedures. Participants of semi-structured interviews also expressed fear of dental procedures such as extractions.

HIV stigma sensitivity. Cross-tabulation tables were used to describe frequency differences across the four subscales of HIV Stigma Sensitivity and the variable assessing the number of years since HIV diagnosis (grouped into the following categories: 1 year or less, 1-2 years, 3 or more years). The results of this analysis are presented below in Table 14. These results indicate that sensitivity to disclosing HIV status may increase over time

due to disclosure experiences. Personalized stigma sensitivity also appears to change depending on how long the participants have lived with HIV; which may also reflect experiences of disclosure and acceptance within social circles.

Table 13

Dental Fears Ranked (N = 70)

Rank	Low Dental Fear (N = 54)		Medium/High Dental Fear (N = 16)	
	Question	**%**	**Question**	**%**
1	3	9.4	**4**	68.8
2	**4**	5.7	7	75
3	5	5.6	11	68.8
4	6	5.6	**14**	86.7
5	**14**	11.1	**15**	87.5
6	**15**	18.5	**16**	93.8
7	**16**	14.9	**17**	93.8
8	**17**	14.9	**18**	93.8
9	**18**	11.1	**19**	68.8
10	**19**	5.6	20	75

Question Text:

3. Muscles tense when having work

4. **Increased breathing rate**

5. Perspire when having work

6. Nauseated when having work

7. Increased heart rate

11. Being seated in dental chair

14. Seeing the anesthetic needle

15. Feeling anesthetic needle

16. Seeing the drill

17. Hearing the drill

18. Feeling the vibration of drill

19. Having my teeth clean

20. High perceived level of fear

Table 14

Years of Living with HIV Diagnosis (N = 70)

HIV Stigma Sensitivity	<1 year %	1-2 years %	≥3 years %
HIV Disclosure Sensitivity			
Low	12.5	10.5	7.1
Medium/High	87.5	89.5	92.9
Public Attitude Sensitivity			
Low	25.0	15.8	25.0
Medium/High	75.0	84.0	75.0
Negative Self Image			
Low	62.5	78.5	67.9
Medium/High	37.5	22.5	32.1
Personalized Stigma			
Low	56.2	47.4	46.4
Medium/High	43.8	52.6	53.6

Aim 3a Results: Describe Perceived Cultural Competency across Oral Health Professions

Scores for cultural competency for each participant were calculated on a 1-4 point scale for each question, with a "1" indicating lowest perceived cultural competency and a "4" indicating highest perceived cultural competency. Each professional group received a mean rank score for every question using the Kruskal-Wallis test. This mean rank score is a weighted value, computed via Kruskal-Wallis, that reflects a) the number of professionals in each oral health professional category reporting a "4" (highest perceived cultural competency) for every item and b) the sample size of each group. The Kruskal-Wallis test was then also used to compute the mean overall rank across professions for all 28 cultural competency questions. The results of this analysis are presented in Table 15. The pediatric dentist ranked highest for overall self-perceived competence in providing

culturally sensitive care for YALWH. Dental hygienists ranked second and general practice dentist were ranked third. More specifically, general dentists felt the most competent in finding information and resources to better serve culturally diverse groups and dental hygienists felt most competent to accurately assess the oral health needs of LGBTQ individuals.

Table 15

Cultural Competency Comparison between Professions (N = 100)

Q No.	Cultural Competency Questions	Mean Rank Score (KS)			Kruskal -Wallis p-value
		General Dentists	Pediatrics	Hygienists	
Q1	How would you rate yourself in terms of understanding how your ethnic/culturally background has influenced the way you think and act?	42.8	59.3	46.8	0.07
Q2	How would you rate your understanding of the impact of the way you think and act when interacting with patients of ethnically/culturally diverse groups?	41.7	52.2	50.1	0.25
Q3	Establishing trust in patients is essential to providing oral healthcare for patients of all ethnically/culturally diverse groups.	46.0	50.8	47.1	0.67
Q4	Good oral health has the same meaning for patients of all ethnically/culturally diverse groups.	59.3	43.2	43.3	0.02*
Q5	Promoting a patient's freedom of choice in treatment options is a goal to strive for in oral healthcare.	49.3	43.5	48.9	0.69
Q6	In general, oral healthcare should be directed toward providing culturally sensitive practices to patients of all ethnically/culturally diverse groups.	49.4	49.6	46.6	0.85
Q7	How would you rate your understanding of "patient management" for treating patients from ethnically/culturally diverse groups?	50.2	56.0	43.8	0.18
Q8	Oral healthcare problems vary within different ethnic/cultural groups.	43.5	51.7	48.3	0.49
Q9	At the present time, how would you rate your own understanding of the following terms: Please check only one answer for each term: -Culture	51.4	52.4	44.5	0.35
Q10	At the present time, how would you rate your own understanding of the following terms: Please check only one answer for each term: -Ethnicity	48.7	49.3	47.1	0.93

Table 15 (continued)

Q No.	Cultural Competency Questions	Mean Rank Score (KS)			Kruskal-Wallis p-value
		General Dentist	Pediatrics	Hygienist	
Q11	At the present time, how would you rate your own understanding of the following terms: Please check only one answer for each term: -Racism	43.8	50.1	49.6	0.57
Q12	At the present time, how would you rate your own understanding of the following terms: Please check only one answer for each term: -Prejudice	43.1	49.1	49.5	0.52
Q13	At the present time, how would you rate your own understanding of the following terms: Please check only one answer for each term: -Pluralism	52.5	50.2	44.6	0.40
Q14	At the present time, how would you rate your own understanding of the following terms: Please check only one answer for each term: -Cultural Encapsulation.	54.5	44.1	45.7	0.29
Q15	At the present time, how would you rate your own understanding of the following terms: Please check only one answer for each term: -Culturally Diverse	49.4	52.3	45.6	0.59
Q16	At the present time, how would you rate your own understanding of the following terms: Please check only one answer for each term: -Oral Healthcare Practice	47.7	51.0	46.1	0.76
Q17	At the present time, how would you rate your own understanding of the following phrase: Culturally Diverse Oral Healthcare Practices?	51.8	51.8	44.4	0.38
Q18	At the present time, how would you rate your own understanding of the following term: Culturally Diverse Patients?	47.2	61.3	43.6	0.04*
Q19	In dentistry, patients from different ethnic/cultural groups should be given the same treatment	58.7	36.1	45.2	0.01*
Q20	How well would you rate your ability to accurately identify your own culturally biased assumptions as they relate to your professional practice?	49.2	44.0	48.8	0.75

Table 15 (continued)

Q No.	Cultural Competency Questions	Mean Rank Score (KS)			Kruskal-Wallis p-value
		General Dentist	Pediatrics	Hygienist	
Q21	How would you rate your ability to effectively secure information and resources to better serve patients of different ethnic/cultural groups?	52.4	46.1	46.2	0.56
Q22	How would you rate your ability to accurately assess the oral healthcare needs of women?	46.1	37.7	52.9	0.07
Q23	How would you rate your ability to accurately assess the oral healthcare needs of men?	49.6	37.7	52.9	0.29
Q24	How would you rate your ability to accurately assess the oral healthcare needs of young adults and adolescents?	40.5	57.8	48.7	0.05*
Q25	How would you rate your ability to accurately assess the oral healthcare needs of gay, lesbian, bisexual and transgender individuals?	46.8	37.8	52.5	0.10
Q26	How would you rate your ability to accurately assess the oral healthcare needs of patients with disabilities?	40.7	56.9	48.9	0.08
Q27	How would you rate your ability to accurately assess the oral healthcare needs of persons who come from low socioeconomic backgrounds?	47.2	51.5	47.2	0.79
Q28	How would you rate your ability to identify your own strengths and weakness of oral healthcare treatment planning for persons from different ethnically/culturally diverse groups?	44.9	51.6	46.6	0.62
	Overall Mean Ranks (KS)	**48.9**	**51.4**	**46.3**	**0.78**

KS: Kruskal-Wallis test was performed per question to rank each profession and to compute an overall mean rank.

*Corresponding for those results meeting criteria at the $p \leq .05$ level:

Kruskal-Wallis test-statistics for significant Questions: Q4 $K = 7.664$; Q18 $K = 6.703$; Q19 $K = 9.271$; Q24 $K = 5.874$

Aim 3b Results: Describe and Compare HIV Knowledge across Oral Health Professions

HIV knowledge scores were computed from the total of three questions. Again, the Kruskal-Wallis test was used to rank each professional group by the number of oral health professionals with the correct response, while also accounting for each group's sample size. The results of this analysis are presented in Table 16. General dentists had the highest mean rank, with dental hygienists ranking second, and pediatric dentists third. Significant differences across the three groups regarding the proportion of participants getting the correct response was observed for question 1.

Table 16

Aim 3B: Ranking of HIV Knowledge by Oral Health Profession (N = 100)

Profession	**HIV Knowledge Ranking^ Mean Rank Scores (KS)**			**Overall Mean Rank Scores (KS)**
	Question 1	**Question 2**	**Question 3**	
General Dentist	46.4	48.5	47.1	50.6
Pediatrics	35.4	43.5	45.9	36.9
Hygienist	50.6	48.4	45.4	49.7
p-value	**0.05***	**0.36**	**0.94**	**0.13**

KS: Kruskal-Wallis test

^Total of 3 questions

1. An HIV infected person with no AIDS diagnosis is defined as an individual with:
2. Which is the most common oral infection seen in patients infected with HIV?
3. Plasma viral load can offer information about which of the following?

*Corresponding Kruskal-Wallis test-statistic for those results meeting criteria at the $p < .05$ level: $K = 7.154$

Aim 3c Results: Compare Perceived Barriers to Oral Healthcare Services for YALWH among Oral Health Professions

Perceived barriers to care were ranked by frequency and compared across three oral health professions. The results of this analysis are presented in Table 17. A patient's lack of reporting their complete medical histories was identified by all dental professions as a barrier to providing care. Dental fear was the second most often cited perceived barrier.

Table 17

Aim 3c: Oral Health Professional Perceived Barriers (N = 100)

RANK	ALL		GD		PD		RDH	
	Barrier*	%	Barrier*	%	Barrier*	%	Barrier*	%
1	3	80.9	7	85.2	3	70.6	4	89.6
2	4	76.8	1	81.5	7	50	3	87.5
3	7	65.3	4	77.8	2	47.1	6	81.3
4	6	63.8	3	74.1	1	44.4	2	62.5
5	1	62.1	6	55.6	4	44.4	7	60.4
6	2	54.3	2	44	6	23.5	1	58.3
7	5	5.3	5	11.1	5	0	5	4.3

GD: General Dentist; PD: Pediatric Dentist; RDH: Registered Dental Hygienist

***Barrier Key:**

1. Frequently missed appointment
2. Do not know there HIV status
3. Do not report there HIV status
4. Do not complete their medical history honestly
5. Are not welcomed in my practice
6. Often do not have dental insurance
7. Are frequently fearful during dental visits

Aim 4 Results: Describe the Perceived Role of, Barriers to, and Facilitators of Oral Healthcare Services for YALWH

Qualitative analysis methods were used to provide results of a dental clinic support staff focus group. The results of this analysis are presented on Table 18. Patient low health literacy was reported as an important barrier to care by dental support staff. They perceived their role as facilitators of positive dental experiences, and reported provider communication skills as an important support factor for normative dental care.

Table 18

Dental Staff Focus Group Results (N = 6)

Category	Codes	Themes
Barriers	▪ Information for Patient ▪ Communication ▪ Knowledge of Needs ▪ Unwelcomed	▪ Lack of Privacy ▪ Long Wait Times ▪ Lack of Information ▪ Disinterested Provider ▪ Lack of Insurance
Role in Care	▪ Comfort ▪ Communicate ▪ Privacy	▪ Welcome Patient ▪ Help Patient Feel Comfortable ▪ Inform Patient of Services ▪ Inform Patient about Clinic Appt. ▪ First Impression ▪ Offer Privacy ▪ Individual Consideration
Facilitators	▪ Communication Skills ▪ Knowledge ▪ Privacy	▪ Welcoming Atmosphere ▪ Feeling of Understanding ▪ Privacy ▪ Understanding Care ▪ Help with Insurance ▪ Compassionate Dental Providers

Chapter V

DISCUSSION

The results of this dissertation contribute to the current limited literature that focuses on oral healthcare among YALWH in the U.S. Specifically, this study sampled YALWH, oral healthcare professionals, and dental staff to identify the social structures, personal resources, and personal health beliefs that shape access and utilization of oral healthcare services among YALWH. This chapter summarizes the key mixed-methodology findings and presents limitations of the present study. Implications of this work for future research and the field of oral health and health education are also presented.

Oral Health-Related Behaviors

In this dissertation, the researcher collected data from 70 young adults between the ages of 17 and 25 years of age who were living with HIV. The participants, mostly male and of Hispanic and Black race, were all patients of a comprehensive healthcare clinic located in northern Manhattan. The overwhelming majority (87%) of study participants expressed the importance of oral health in their lives during the qualitative interviews. Participants reported that a clean mouth with straight white teeth makes a great deal of difference in how they judge others and, they assume, how others judge them. The professional care they sought was not consistent with the value for oral health expressed; survey responses indicated that only 50% had a dental exam or cleaning in the

last year and just a little more (57%) reported they had a regular place for dental care. These results are similar to the results of the National Health Interview Survey that reported 59% of young adults had a dental visit in the previous 12 months (Vujicic et al., 2014). The qualitative interviews suggested that other life issues may be more important than dental visits. Dental providers' poor communication regarding therapies as well as their inability to express empathy for their patients were other barriers patients mentioned, as the following excerpts from a patient interview and the focus group reveal.

> "I have only been in New York for about a year. I am still feeling things out, but the first thing I did was make sure that, you know, I was taking care of the HIV situation because that to me is far more, way more serious than anything else personally. Everything else falls in behind." (YALWH structured interview quote 12)

> " I feel like oral health is so important. It's just, honestly when I look at someone that would potentially be my partner, hands and mouth are just something that I look at all the time. A man with beautiful with a beautiful mouth is one of the most attractive things ever. Your mouth is just part of your body and just like you have to track your blood I would love to check my dental." (YALWH structured interview quote 12).

> Patients are really interested in whitening. One asked, "Can I get my teeth cleaned? Look at this tooth; you see this is the one that's very yellow? Can somebody do something to clean the yellow?" "Yes," I told him, "but first we need to fix this one with the big hole in it." (Dental staff focus group quote 1)

> " Did you understand what the dentist was telling you?" "Yes, cause they would explain it for detail, so I was like, was getting it little by little even though I had like big words, I was like what? But they explained it good, you know?" (YALWH structured interview quote 13).

Quantitative data revealed that YALWH patients' daily oral health preventive behaviors were high, with 97.3% brushing, 53% flossing, and 57% regularly using fluoride mouth rinses. The One-hundred percent (n = 26) of the semi-structured interview

participants subsequently reported that as young children (< 10 years of age) their mothers influenced their daily oral health behaviors by demonstrating tooth brushing. Eighteen of these structured interview participants expressed positive experiences with dental professionals as young children, including having a family dentist and receiving school-based oral health services in lower school. Descriptions of positive experiences included supportive comforting attitudes and a willingness by dental providers to explain treatments. Study interview participants were delighted to share how their moms stressed the importance of oral health; this may be associated with the current high rates of daily oral health behaviors practiced, as the following excerpt from a patient interview revealed.

> "Yeah, my mom, always my mom. My mom was always there, she taught me how to do it, you know, brush my teeth up and down and stuff like that. . . . *Barney* show too, but actually my mom taught me to go in circles and to floss." (YALWH structured interview quote 14)

> "A bad experience is one I'm about to face getting the whole needle and injection and then doing the extraction. Uh-huh, I don't like that part!" (YALWH structured interview quote 15).

Tobacco use, including cigarettes and hookah, was reported by 21% and 20% respectively of the YALWH survey participants (n = 70). Although only 4.3% reported using cigars, when prompted, many reported using tobacco leaves from cigars to roll marijuana. Substance use as a factor of oral healthcare service utilization was not examined as a specific aim in this study, as such so no additional items on drug use was asked during the survey or interviews. Tobacco use in the general young adult population was found to also be reduced, but still enough of a concern that this health risk behavior

was included in Healthy People 2020's 41 core indicators for adolescent and young adult health (NRC & IOM, 2009, 2014).

Overall, YALWH participants' consumption of sugar-sweetened beverages as well as sugar-sweetened candy and gum was found to be high (78.6% and 80%, respectively). Further, only 8 of the 26 qualitative interviewees mentioned efforts to maintain healthy diets and, when probed further, their knowledge of healthy fruits and vegetables was limited. This may be explained by housing security issues reported: 47.1% said they were living in friends' houses, temporary housing or shelters, which made purchasing, storing, and preparing healthy foods a challenge.

"They really don't have food sometimes in the group home and sometimes you gotta like buy your own stuff, I get stuff sometimes from my grandma" (YALWH structured interview quote 16).

Perceived Barriers to Oral Healthcare

Not having dental insurance and not being able to afford oral healthcare were the most frequently reported barriers to oral healthcare, as indicated by data from the YALWH patient surveys (36.4% and 27.3%, respectively) as well as the qualitative interviews. It is unclear, however, if the YALWH participants were referring to a instance prior to joining the health clinic utilized in this study, because the enrollment in a Medicaid-managed care organization is part of this clinic's initial patient registration process. It is possible that these patients may not have been clear that dental care is covered by Medicaid health insurance plans in New York State.

"Have you been going for regular checkups?" "No, I would love to. I haven't been to the dentist in almost two, three years now. The most important thing I would have to say it's just the money part, the billing and you know being scared that my Medicaid wouldn't cover it". (YALWH Structured interview quote 17).

It is also not clear from survey responses if lack of insurance indicated that these patients may have been expressing an inability to pay for treatments not covered by Medicaid. However the limited number of treatments covered by Medicaid dental insurance was mentioned by all 26 participants during the YALWH qualitative interviews. Patients expressed feelings of frustrations during structured interviews that dental exams and cleanings were paid through Medicaid dental insurance, but other needed services were not covered. Table 19 presents how the Affordable Care Act has recently enabled all young adults to afford dental care services through their parents' private dental insurance. However, YALWH, whether living with their parents or independently, frequently do not have access to private dental insurance; possibly due to high numbers living in poverty. This lack of ability to afford dental services was also found in previous studies conducted with adult patients living with HIV (Fox et al., 2012). This may be a consideration for policy makers to increase treatments offered through Medicaid dental insurance.

Table 19

Effect of the Affordable Care Act's Dependent Coverage Policy on Young Adults

	Year							
	2010		2011		2012		2011	2012
Dependent Variable	Adults Aged 19-25 (%)	Adults Aged 26-34 (%)	Adults Aged 19-25 (%)	Adults Aged 26-24 (%)	Adults Aged 19-25 (%)	Adults Aged 26-34 (%)	Difference-in-differences Regression Estimate (Percentage Points)	
Private dental benefits coverage	37.5	46.0	42.4	45.7	43.9	45.7	5.6***	6.9***
Dental visit in the past 12 months (utilization)	54.3	56.2	58.0	56.2	59.0	57.1	2.8*	3.3*
Financial barriers to dental care	18.9	18.4	14.7	18.5	14.1	17.6	-2.1*	-2.0*

Estimates and SEs accounted for the complex sampling design of the NHIS. The authors used linear probability regression models using difference-in-differences and conducted all analyses using the statistical software STATA, version 12. Regressions control for age, education, ethnicity/race, sex, marital status, and region. Total number of observations is 92,171 (private dental benefits), 38,204 (dental visit), and 38.331 (financial barriers).

*$p < 0.10$
**$p < 0.05$
***$p < 0.01$

Source: Vujicic, M., Yarbrough, C., & Nasseh, K. (2014). The effect of the Affordable Care Act's expanded coverage policy. *Medical Care, 52,* 8.

Social Factors and Oral Healthcare

Interestingly, education level was found to have a statistically significant association with the variable "dental home". More specifically, those youth with a high school education had a regular place for oral healthcare (65%) versus the YALWH participants in college who reported a regular place for oral healthcare (12.5%) (p = 0.027). These latter YALWH survey participants may be working and taking classes leaving less time for oral healthcare appointments. Other social factors did not appear to

have statistically significant associations with either normative care variable; however there were notable differences in the frequency of YALWH participants engaging in normative care among regular transportation type, level of food security, and type of insurance.

A recent national estimate of homelessness in American reported 10% of those experiencing housing insecurity were between 18 – 24 years of age (NRC & IOM, 2009, 2014). This study samples was considerably higher at 47.1%.Of those who reported living in someone else's home or in temporary housing, 63.3% did not having a regular place for dental care and only 41.0% had visited a dentist in the last 12 months. As mentioned earlier in this study, food security may be related to housing status, as is the lack of stable housing can make it difficult to store or prepare healthy foods. Survey results indicated that 56.7% of those who reported not having enough to eat did not have a regular place for dental care and only 30.8% reported visiting a dentist in the last year.

"I was staying at a transitional home for people who are HIV positive so at that time they were all my age so I have a really good bond with friends I made. We always ate out because there wasn't food their" (YALWH structured interview quote 18).

Lastly, it should be noted that public transportation results as it related to normative oral healthcare may have been over reported in this study as New York City Metro Cards are given to patients at the comprehensive medical clinic and the dental clinic associated with this study. However, this may also indicate that affordable transportation is an important factor for use of oral healthcare services by YALWH.

Personal Beliefs and Oral Healthcare

Although not statistically significant, of those reporting a low sensitivity to disclosing their HIV status, 60% had a regular place for dental care compared with 40% of those with high sensitivity ($p = 0.167$) . Similar trends were observed among other HIV stigma subcategories of sensitivity to public attitudes and personalized stigma experiences. Similar results were reported among the subgroup of YALWH participants who also participated in the qualitative interviews. Participants reporting high personalized stigma sensitivity (those who experienced negative responses from health providers, family, or friends after reporting HIV status) reported having a regular place for care for low ((87.5%) and high ((12.5%) sensitivity levels ($p = 0.027$). It should be noted that the subset of qualitative interview participants reported 90% & 10% respectively.

"Just the way it is. Just look at us different than regular people. I think when you tell them you're HIV positive it's like different look. Like you have to be more careful __ Like I don't feel like we're different than anyone else. Like not that they're going to catch it by you checking out my mouth or whatever the case might be. I just wish that it would be more comfortable for me not to worry about them discriminating whether or not you're gonna help me or not. (YALWH structured interview quote 19).

Dental Fear

The results of the analysis of dental fear scores indicated that YALWH participants reporting low dental fear had a higher number of dental visits over the last

year and were also more likely to have a regular place for dental care than those participants with high dental fear.

After examining the specific items on the dental fear index, it was discovered that the five most reported dental fear topics were the same for those with low fear and those with medium/high fear scores. These items were related to tools used in dental services e.g., anesthetic needles and the dental drill. This is an important consideration for oral health providers to improve the oral healthcare they are prepared to offer YALWH. It may be advisable for all patients to complete a brief dental fear index prior to care so that a patient's specific concerns can guide treatment.

> "I'm just scared of needles, so I really don't, kind of avoid the dentist. Any visit that involves needles is not a good one. Fear most of the time is the reason" (YALWH structured interview quote 20).

Oral Healthcare Professionals: HIV Knowledge and Perceived Barriers

The oral healthcare professionals' perceived ability to provide cultural competent care and levels of HIV knowledge yielded surprising results. The profession (pediatric dentists) that had a higher mean rank score for perceived ability to provide competent care had the lowest mean rank score for HIV knowledge. The most reported barrier to care; across all three professional groups was patients not disclosing their HIV status. This has implications for clinical training for oral health professionals. Greater knowledge and use of universal precautions when providing clinical services might serve to reduce the fear of treating a patient living with HIV. Better communication skills

might also serve to prepare providers to assist patients in completing their medical histories.

Greater knowledge of oral diseases associated with HIV would further aid dental professionals in the provision of better care for HIV+ patients; and possibly serve to decrease the number of young adults currently undiagnosed. Providing more competent oral health care for YALWH could potentially increase the identification of failed HIV therapies, whether from lack of adherence or virus resistance. It is also important to point out that policy makers should consider expanding dental professional's scope of practice to include HIV screening in the dental setting.

Common Perceived Barriers to Care across Three Study Groups

There were three perceived barriers to oral healthcare that were identified by all study groups: dental insurance, HIV disclosure, and dental fear (see Figure 4).

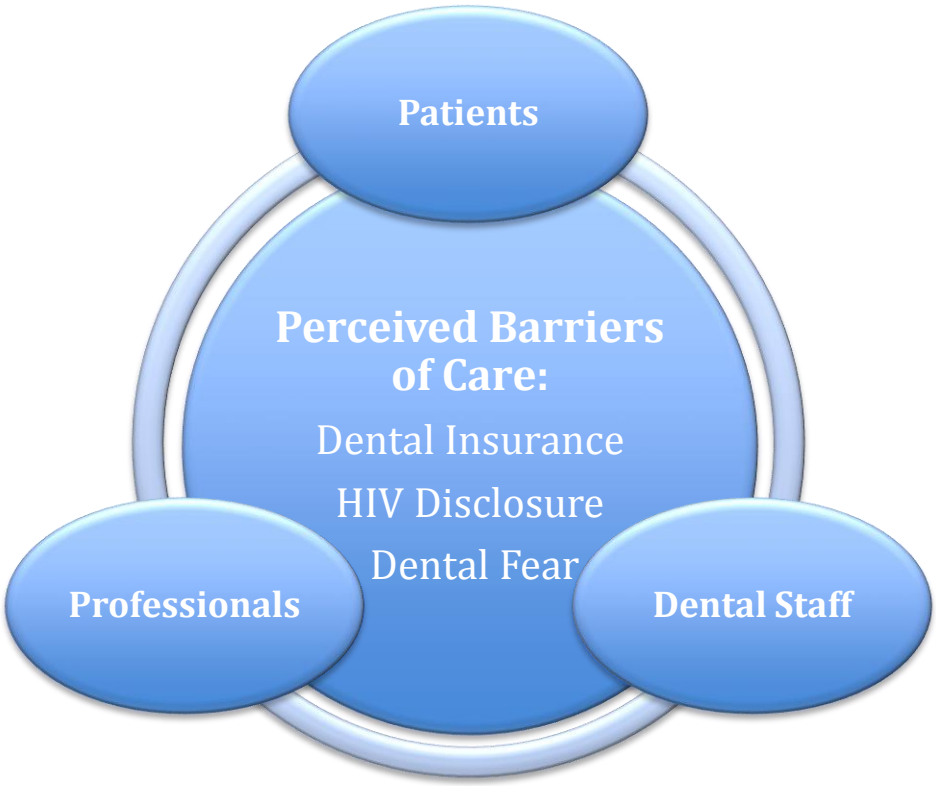


Figure 4. Perceived barriers to care

Dental insurance. YALWH patients noted that the limited coverage for dental treatments by Medicaid dental insurance policies eliminates their ability to receive many therapies, thus leaving many YALWH living with active infections and/or requiring teeth extractions. In addition to being painful, such oral health issues can also lead to an

inability to chew properly, which can influence their selection of foods and negatively impact their overall health. Although not always an immediate implication, the facial support structures are lost as a result of missing dentition and can affect youth's self-image as well as future employment opportunities.

A secondary issue associated with dental insurance that was identified by the YALWH participants, was the lack of understanding of the Medicaid health insurance program. Participants were often unaware that dental care is offered as part of medical plans. Finding a dental provider that accepts Medicaid is challenging, with approximately one-quarter of the survey participants identifying it as a reason they did not get needed care. Young adults in general have been reported to have low utilization of oral healthcare services; these present findings may offers some additional insight into barriers that this specific population faces.

Dental insurance, or the lack of it, was similarly identified by the study's sample of oral healthcare professionals as a perceived barrier because they believed many YALWH do not have dental insurance and cannot afford to pay out of pocket. Dental providers in private practices do not have the ability to provide care for patients who cannot pay for services, thereby limiting the number of providers available.

The dental clinic staff also identified dental insurance as a barrier to care, citing young adults' lack of understanding of what kind of insurance they have and how to use it. The staff reported that they often find that YALWH come to the dental clinic expecting therapies that are not covered and are discouraged when they are told they would need to pay for all or part of the needed care. Dental staff also observed that

YALWH often are not aware that their NYS Medicaid medical coverage includes dental care.

HIV disclosure. The act of disclosing an HIV positive diagnosis was very much a concern for the sample of YALWH patients, as reflected in the survey results and the qualitative interviews. This study also found that disclosure sensitivity appears to change with the number of years one has lived with HIV. Qualitative interview participants expressed a specific desire to be able to provide information on their medical history with more privacy than presently offered. Disclosure sensitivity may also be a reason participants reported a desire to have one dental provider, thereby limiting the number of times they would be asked to share sensitive information.

Oral healthcare professionals perceived the lack of reporting of an HIV positive diagnosis as a barrier to their providing care. This perception may indicate a single-sided focus on the delivery of healthcare services on the part of dental professionals. It may also indicate the need for additional training on methods for effective patient communication.

The dental clinic staff unanimously identified privacy as a concern about providing care for YALWH. They also stated that providing an environment that will encourage this patient population to complete treatment plans and return for routine examinations is an important component of providing care.

Dental fear. YALWH patients identified fear of dental therapies such as extractions or endodontic therapies (root canal therapies), as well as the instruments

traditionally used during dental treatments, as factors that discourage them from seeking care. Also, the increased probability that they could need more invasive treatments as a result of delayed treatments creates - what has been referred to in the literature as - the cycle of fear (Armfield, 2007). Studies of dental fear have reported frequently that it is a fear acquired during early childhood (Milgrom, Vighehsa & Weinstein, 1992). All the qualitative interview participants (n = 26) reported having positive experiences as children, with most negative experiences taking place as young adults $\geq$ 17 years of age. Oral health education and improved provider communication skills may together improve patient understanding of dental instruments used during common dental procedures, as well as therapies provided, thus serving to create a more favorable environment for YALWH to receive care.

The three dental professional groups all reported dental fear as the third most frequent barrier to providing care. The dental clinic staff also reported that they recognized fear in young adults coming to the clinic for care and often try to do their best to reassure them that they are safe and in good hands.

Study Limitations

There were some limitations to the present study that warrant consideration when interpreting and generalizing the study's key findings.

Study Design:

The cross-sectional design limited the researcher's ability to establish causation due to the lack of long-term study results.

Patient Recruitment:

The researcher's role as a health educator in this clinic enabled the young adults to feel secure to complete survey items but may have also resulted in social desirability bias.

Data Collection

Recruitment of patients receiving HIV therapies may have resulted in selection bias as these patients may have greater higher health literacy levels than those not currently in active treatment.

Delimiting the YALWH data collection to one medical clinic in one urban located hospital center limits the ability to generalize the findings of this study to all YALWH. It should be noted, however, that of the 100 current active patients at this clinic, the researcher recruited 70. Thus, this sample was highly representative of the population of YALWH treated at this clinic.

Analysis

The analysis of professional perceived cultural competence mean rank scores included each of the 28 items in addition to an overall mean score comparison. This

appears to increase the risk for type one error, however this comparison was intended to provide descriptive results not test for significant differences.

Future research may require a Bonferroni correction post hoc analysis if the size of the compared groups are more evenly distributed.

Future Research Directions

This dissertation contributes to filling the gap in the literature by identifying both facilitators and barriers to oral healthcare services among HIV positive young adults from the perspectives of the patients, dental care providers, and dental support staff. Given the established relationship between poor health literacy and medical care access, additional research on the possible associations between young adults' health literacy regarding medical/dental insurance programs and their low rates of insurance coverage and healthcare utilization is warranted.

The present research findings also suggest that more effective communication on current healthcare coverage systems may be needed for young adults. For example, it is unclear if young adults who are living with a chronic disease such as HIV are not receiving oral health services because they cannot navigate the health insurance systems or have little understanding of the types of coverage available.

Similarly, future research needs to explore the overall health effects of limited Medicaid coverage for young adults living with chronic conditions. This field would also benefit from understanding the long term cost effectiveness of not providing services that save oral health integrity of young adults. Lastly, research exploring effective preventive healthcare services specifically for young adults between the ages of 19 and 25 years of

age is important, as most research to date includes this age group with adolescent populations or adult populations.

Implications for Health Education

Oral health diseases are treatable and preventable. Indeed, the topic of oral health provides great opportunities for health education, yet is often overlooked as a viable component of general health. Healthy People 2020 has included oral health, adolescent and young adult health and HIV in its' topic areas. Specifically to prevent and control oral diseases, improve access to preventive services and care; improve the healthy development of adolescents and young adults; and prevent HIV infection and related illnesses (US Dept. Health and Human Services, HP2020). Integration of oral health with other health messages may improve the likelihood of meeting these goals.

Specifically, health educators should consider providing more comprehensive health information for varying patient populations by incorporating oral health in all disease prevention messages. The topic of oral health can be related to many healthy lifestyle information messages, such as diet, tobacco product use, diabetes education, cancer therapy instructions, and cardiovascular disease post-treatment instruction and prevention messages. Indeed, chronic diseases including cardiovascular diseases (CVD), HIV, and diabetes mellitus all have been reported to have links to periodontal disease and dental decay (Petersen & Ogawa, 2000). The relationships may be related to microvascular changes, the composition of gingival crevicular fluid, the host response system, changes in oral micro-flora (Vanchit & de Bedout, 2013). Inflammation is a

common pathophysiology of periodontal disease, diabetes mellitus and CVD and has been associated with increased risk for these diseases independent of shared risk factors such as smoking, poor nutrition and socioeconomic status (Mochari, Grbic & Mosca, 2008). Health educators could play a key role in integrating oral health with other health promotion and disease prevention messages.

Implications for Oral Health Professionals

Fear of dental instruments and clinical therapies proved to be more descriptive of patients' concerns regarding oral healthcare services. It may be advisable to include a brief survey of patients' dental fear as part of all medical histories. This would better prepare oral health providers to address the needs of individual patients. Healthcare education today focuses on inter-professional education and inter-professional practice; although in reality the dental profession is not well integrated with other health care disciplines. The integration of oral health with overall healthcare needs to be emphasized.

Health literacy can be affected by individual and systemic factors such as provider communication skills, provider knowledge of health topics, cultural influences, limitations of health care delivery systems and the expectations of the individual patient. Oral health providers need to consider these factors in their efforts to improve their own health literacy and that of their patients.

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Appendix A

Patient Survey

Default Question Block

Interview Date

We are doing this study to see what your thoughts and experiences have been regarding your dental care.

There are a total of 5 sections of questions to complete with a total of 44 questions.
Thank you for your help.

Section 1: Your Dental Experiences

Do you have a regular place to receive dental care?

Yes
No
Not sure

Where do you go for dental care?

I do not have a regular place
A dentists' office
A health center or clinic
An emergency department
A mobile van
A dental clinic
A hospital dental clinic

Has there been a time when you needed dental treatment but did not get it?

No
Yes

If you needed dental care and did not get it, what was the reason(s) (Please check all that apply)

I could not afford it
I couldn't find an HIV friendly dentist
I did not know where to find dental care
I did not have transportation
I could not get an appointment at a time I could make it
I did not think it was important
I was worried about my privacy
I did not feel well enough to go to a dentist
I was afraid of finding out something was wrong
I did not want to go to the dentist
Family responsibilities were more important
I had no insurance
I was in prison
I was addicted
I had a previous bad experience
Fear of the dentist
Other responsibilities were more important
Other _____

Of everything you just mentioned, which was the most important reason you did not get dental care?

Section 2: Your last dental experience:

When was the last time you saw a dentist?

___ Month _ _ _ _ Year

Less than 6 months
6 months to 1 year
More than 1 year up to 2 years
More than 2 years up to 5 years
More than 5 years
Never received dental care

If you had a dental visit in the last year: (please choose the best answer for each question) If you have **not** had a dental visit in the last year skip to **Section 3 About Your Mouth**

	Yes	No	Not Sure
Was this visit for an emergency? (an infection or Pain)	○	○	○
Was it in an emergency department?	○	○	○
Was it in a hospital dental clinic?	○	○	○
Was your care provided by a dentist?	○	○	○
Was it in a private dental office?	○	○	○
Was your care provided by a dental hygienist?	○	○	○
Did your provider explain things in a way that was easy for you to understand?	○	○	○
Did your provider listen carefully to you?	○	○	○
Did your provider show respect for what you had to say?	○	○	○
Was the provider as helpful as you thought they should be?	○	○	○
Did the reception person and office staff treat you with courtesy and respect?	○	○	○
Did your case worker or social worker refer you for dental care?	○	○	○

If you received dental care in an emergency department during last year, did you receive follow-up care?

No

Yes

Did not receive care in an ED

Section 3: About your Mouth

How would you describe the health of your teeth and gums?

Excellent

Very Good

Good

Fair

Do you brush your teeth?

Yes
Yes twice a day
Yes once a day
No

Does the toothpaste you use have fluoride in it?

Yes
No
Not sure

Do you floss your teeth?

Yes
No
Do Not Know

Do you smoke cigarettes?

Yes
No

Do you use other tobacco products?

Yes
No
Chewing tobacco
Hookah
Cigars
Little Cigars
Pipe
Snuff

Do you drink soda with sugar?

Yes
No

Do you eat hard sugar candy or chew gum with sugar?

Yes
No

Do grind or clench your teeth?

Yes
No
Not Sure

Do you rinse with a fluoride mouth rinse?

Yes
No

Do you have removable denture or appliances?

No
Yes
Not Sure

In the past 3 months how much pain or distress have your teeth or gums caused you?

None at all
A little bit
Some
Quite a bit

During the past 3 months
How often have you experienced the following difficulties because of pain in your mouth?

	Never	Hardly Ever	Sometimes	Often	All of the Time
Found it difficult to relax	○	○	○	○	○
Have had to avoid eating foods	○	○	○	○	○
Have avoided going out	○	○	○	○	○

Have problems with your mouth made it difficult for you to take your medications?

I do not take medications
Never
Sometimes
Often
All of the time

Section 4: About You

In what year were you born?

Year _ _ _ _

What is your gender?

Male
Female
Transgender
Do not wish to respond

How would you describe your race/ethnicity?

Black or African American

Asian

American Indian or Alaska Native

Native Hawaiian or Pacific Islander

White (non Hispanic)

Multiracial/Biracial (specify) _____

Other (specify) _____

Hispanic

How many years of school have you completed?

Elementary up to and including High School

Vocational School

College

Other (specify)_____

What language do you speak most of the time, with friends and family?

English

Spanish

French

Other (specify)_____

Creole/French Creole

Are you currently employed?

Full time (35+ hours per week)

Part time

Unemployed

Disabled

Other (specify)_____

Where do you live right now?

Own home

Someone else's home or apartment

Temporary housing (residential program/transitional housing/single room occupancy hotel)

Shelter

On the streets, in a car, in a park, moving around

Other (specify)_____

How long have you lived in the place you are living now?

Less than 6 months

6 months to 1 year

More than 1 year

Community Questions

The following are things that people might say about their neighborhood we are referring to the neighborhood that you are currently living in.

Please tell me if you:

Agree strongly, Agree ,Disagree Strongly or Disagree (Please check only one for each question)

	Agree Stongly	Agree	Disagree Strongly	Disagree
1. I think my neighborhood is a good place for me to live	○	○	○	○
2. My neighbors and I want the same thing from the neighborhood	○	○	○	○
3. I feel at home in my neighborhood	○	○	○	○
4. People in my neighborhood generally do not get along	○	○	○	○
5. It is very important to me to live in this particular neighborhood	○	○	○	○

How long did it take you to get here today?

Minutes _____

Hours _____

Do not know

Not sure

How did you get here today?

Walked

Car

Bus

Van

Taxi

Subway

Other (Specify) _____

Getting enough food can be a problem for some people

Which of the following statements best describes the food eaten in your household in the last 6 months

I/we had enough of the kinds of food I/we want

I/we had enough but not always the kinds of food I/we want to eat

I/we sometimes did not have enough to eat

I/we often did not have enough to eat

Section 5: About your dental and medical care

Have you ever been tested for:

	Yes	No
Tuberculosis (TB)	○	○
Hepatitis C	○	○
HIV	○	○

When did you find out you were HIV+ ?

_____ (month)_____(year)

I have never tested positive for HIV

I do not know

Where do you usually see a medical provider for HIV? (Please check one)

Health Center or Clinic

Hospital Clinic

Emergency Department

Private physicians office

I do not have a regular place for care

Other (specify) _____

What kind, if any, health insurance do you have for your medical care? (Check all that apply)

None

Medicare

Medicaid

Private Insurance

Do not know

What kind, if any, dental insurance do you have?

None

Medicaid (specify) _____

Private Insurance

Medicare

Do Not know

Since you tested positive has there been a time when you needed dental care but did not get it?

No

Yes

I have not tested positive

How much do you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I have been hurt by how people reacted to learning I have HIV	O	O	O	O	O
I have stopped socializing with some people because of their reactions of my having HIV	O	O	O	O	O
I have lost friends by telling them I have HIV	O	O	O	O	O
I am very careful who I tell that I have HIV	O	O	O	O	O
I worry that people who know I have HIV will tell others	O	O	O	O	O
I feel that I am not as good a person as others because I have HIV	O	O	O	O	O
Having HIV makes me feel unclean	O	O	O	O	O
Having HIV makes me feel that I'm a bad person	O	O	O	O	O
Most people think that a person with HIV is disgusting	O	O	O	O	O
Most people with HIV are rejected when others find out	O	O	O	O	O

Dental Fear and You

	Click to write Column 1				
	Never Not At All	Once or Twice or a little	A few times or somewhat	Often or much	Nearly every time, or very much
Has fear of dental work ever caused you to put off making an appointment?	O	O	O	O	O
Has fear of dental work ever caused you to cancel or not to appear for an appointment?	O	O	O	O	O
When having dental work done my muscles become tense	O	O	O	O	O
When having dental work done my breathing rate increases	O	O	O	O	O
When having dental work done I prespire	O	O	O	O	O
When having dental work done I feel nauseated and sick to my stomach	O	O	O	O	O
When having dental work done my heart beats faster	O	O	O	O	O

Do you experience fear when:

	Click to write Column 1				
	Never	Once or twice or a little	A few times or somewhat	Often or much	Nearly every time or very much
Making an appointment for dentistry	○	○	○	○	○
Approaching the dental office	○	○	○	○	○
Sitting in the waiting room	○	○	○	○	○
Being seated in the dental chair	○	○	○	○	○
The smell of the dentist's office	○	○	○	○	○
Seeing the dentist walk in	○	○	○	○	○
Seeing the anesthetic needle	○	○	○	○	○
Feeling the anesthetic needle injected	○	○	○	○	○
Seeing the drill	○	○	○	○	○
Hearing the drill	○	○	○	○	○
Feeling the Vibration of the drill	○	○	○	○	○
Having my teeth cleaned	○	○	○	○	○
All things considered, how fearful are you of having dental work done?	○	○	○	○	○

Appendix B

OH YALWH Patient Interview Guide

Introductory script

Thank you for agreeing to participate in our study *HIV & Adolescent Oral Health.*

I am conducting this study here at your clinic to learn more about your dental experiences and how important having a healthy mouth is to you.

All of your answers are completely confidential and your name will not shared. If it okay with you, I will record our conversation to ensure we have accurately captured your responses. The information I gather will be used to better understand what young adults living with HIV need from dental providers and for healthy mouths.

If you agree to participate do we have permission to audiotape our interview?

All interviews will be transcribed and coded to protect your identity and privacy.

1 .a. How important has oral health care been to you?

b. Growing up, in your family how important was taking care of your mouth, teeth & gums?

c. Did your parents/relatives ever tell you or show you how to brush your teeth? Did you go to the dentist? How often?

d. Did a dentist or dental hygienist every show you how to take care of your mouth, teeth and gums? When was that?

2. Tell me about your dental and oral health care experience since testing HIV positive.

Probes: Is your experience with dental care providers better, worse or the same since becoming HIV positive?

Can you describe a good experience? Can you describe a bad experience? What are the reasons you have not seen a dentist? (any fears, treatment by dental staff, Affordability)

3. Tell me about your experience at the last dental office or clinic you visited.

Probe: Did you see a dentist or hygienist? Was the dentist/hygienist respectful?

Did the dentist/hygienist tell you about you're the health of your mouth in a way you could understand?

4. Tell me about the staff at the dental office or clinic.

Probe: Were they polite, did you feel they cared about you, were they helpful to you

5. Please describe your overall quality of life.

Probes: Who helps you manage living with HIV? Who do you talk to when you need support or experience difficult times? Who helps you get services that you need? (a case manager, social worker) When and how often do you turn to this person for support? Do these refer to quality of life?

b. Please describe if or how any problems in your mouth have affected your quality of life?

Probes: Have oral health problems caused physical or emotional pain? Please describe.

c. How does living with HIV affect your oral health care? Does taking medication affect your oral health problems*?*

6. Since testing HIV+ have oral health problems affected your participation in any activities? (employment, social activities, daily living) Please give examples.

b.Have concerns or worries about your personal appearance with respect to teeth or otherwise affected your participation?

7. Please describe how you currently care for your teeth and mouth at home.

b. What do you think are good personal oral health care practices (ways to take care of your teeth and mouth)?

8. If you could change one thing about dental care services what would you suggest?

Appendix C

Table of Frequency Distribution

Aim 2: Frequency Distribution of Quantitative and Qualitative Participants					
Factors and Beliefs		**Normative Utilization**			
		N = 70^		**N = 26^^**	
		N	**%**	**N**	**%**
Social Factors					
Transportation					
	Bus or Subway	44	62.9	20	76.9
	Other	26	37.1	6	23.1
Food Security					
	Had enough	44	62.9	16	61.5
	Did not have enough	26	37.1	10	38.5
Employment					
	employed	28	40	11	42.3
	unemployed	44	60	15	57.7
Home Condition					
	Own Home	37	52.9	11	42.3
	Someone else	21	30	8	30.8
	Other	12	17.1	7	26.9
Insurance Status					
	Medicaid	55	79.7	21	80.8
	Other	14	20.3	5	19.2
Education					
	High School	37	52.9	11	42.3
	College	8	11.4	4	15.4
	Other	25	35.7	11	42.3
Personal Beliefs					
HIV Stigma					
	Low Disclosure Sensitivity	37	52.9	12	46.2
	High Disclosure Sensitivity	33	47.1	14	53.8
	Low Public Attitude Sensitivity	33	47.1	7	26.9
	High Public Attitude Sensitivity	37	52.9	19	73.1
	Low Personalized Stigma	57	81.4	19	73.1
	High Personalized Stigma	13	18.6	7	26.9
	Low Negative Self-Image	62	88.6	24	92.3
	High Negative Self-Image	8	11.4	2	7.7

Dental Fear					
	Low	54	77.1	24	92.3
	Medium/High	16	22.9	2	7.7
Rating Oral Health					
	Good-Fair	44	62.9	16	61.5
	Excellent-Very good	26	37.1	10	38.5

^ Complete population

^^ Patients who took part in the Semi-Structured Interviews.

Appendix D

Dental Professional Survey

Default Question Block

This questionnaire is intended to gather data on dental professional's attitudes and knowledge regarding multicultural patient care, treating adolescents/young adults, and oral health and HIV.

There are 3 sections of questions to complete. It should take no more than 15 minutes to complete.
Thank you very much for your cooperation.

Todays Date

Section 1: This section is intended to gather information on multiculturalism and the dental practice

How would you rate yourself in terms of understanding how your ethnic/culturally background has influenced the way you think and act?

Very Limited
Limited
Fairly Aware
Very Aware

How would you rate your understanding of the impact of the way you think and act when interacting with patients of ethnically/culturally diverse groups?

Very Limited
Limited
Fairly Aware
Very Aware

Establishing trust in patients is essential to providing oral healthcare for patients of all ethnically/culturally diverse groups.

Strongly Disagree
Disagree
Agree
Strongly Agree

Good oral health has the same meaning for patients of all ethnically/culturally diverse groups.

Strongly Disagree
Disagree
Agree
Strongly Agree

Promoting a patient's freedom of choice in treatment options is a goal to strive for in oral healthcare.

Strongly Disagree
Disagree
Agree
Strongly Agree

In general, oral healthcare should be directed toward providing culturally sensitive practices to patients of all ethnically/culturally diverse groups.

Srongly Disagree

Disagree

Agree

Strongly Agree

How would you rate your understanding of "patient management" for treating patients from ethnically/culturally diverse groups?

Very Limited

Limited

Good

Very Good

Oral healthcare problems vary within different ethnic/cultural groups

Strongly Disagree

Disagree

Agree

Strongly Agree

At the present time, how would you rate your own understanding of the following terms:
Please check only one answer for each term:

	Very Limited	Limited	Good	Very Good
Culture	○	○	○	○
Ethnicity	○	○	○	○
Racism	○	○	○	○
Prejudice	○	○	○	○
Pluralism	○	○	○	○
Cultural Encapsulation	○	○	○	○
Culturally Diverse	○	○	○	○
Oral Healthcare Practice	○	○	○	○

At the present time, how would you rate your own understanding of the following phrase: Culturally Diverse Oral Healthcare Practices?

Very Limited

Limited

Good

Very Good

At the present time, how would you rate your own undestanding of the following term: Culturally Diverse Patients?

Very Limited

Limited

Good

Very Good

In dentistry, patients from different ethnic/cultural groups should be given the same treatment

Strongly Disagree
Disagree
Agree
Strongly Agree

How well would you rate your ability to accurately identify your own culturally biased assumptions as they relate to your professional practice?

Very Limited
Limited
Good
Very Good

How would you rate your ability to effectively secure information and resources to better serve patients of different ethnic/cultural groups?

Very Limited
Limite
Good
Very Good

How would you rate your ability to accurately assess the oral healthcare needs of women?

Very Limited
Limited
Good
Very Good

How would you rate your ability to accurately assess the oral healthcare needs of men?

Very Limited
Limited
Good
Very Good

How would you rate your ability to accurately assess the oral healthcare needs of young adults and adolescents?

Very Limited
Limited
Good
Very Good

How would you rate your ability to accurately assess the oral healthcare needs of gay, lesbian, bisexual and transgender individuals?

Very Limited
Lilmited
Good
Very Good

How would you rate your ability to accurately assess the oral healthcare needs of patients with disabilities?

Limited
Very Limited
Good
Very Good

How would you rate your ability to accurately assess the oral healthcare needs of persons who come from low socioeconomic backgrounds?

Limited

Very Limited

Good

Very Good

How would you rate your ability to identify your own strengths and weakness of oral healthcare treatment planning for persons from different ethnically/culturally diverse groups?

Limited

Very Limited

Good

Very Good

Please be sure to continue to next page for Section 2 and 3. When you have reached the end of the survey click the arrow on the bottom right to submit your responses.

Section 2 This section is intended to gather demographic information on dental professionals completing this questionnaire.

Which best describes your professional specialty?

AEGD Resident
Pediatric Resident
General Practice Dentist
Pediatric Dentist
Registered Dental Hygienist
Other (specify)_____

When did you graduate from dental/dental hygiene school?

Where do you practice? (Please select all that apply)

Private Practice
Hospital Clinic
Specialized practice (specify)
Not in clinical practice

What is your gender?

Male
Female

What is your race?

Black or African Americn

Asian

American Indian or Alaska Native

Native Hawaiian or Pacific Islander

White

Multiracial

Other (specify)_____

If you selected Black or African American above, please specify:

African

African American

Caribbean/West Indian

Other (specify)_____

Are you Hispanic or Latino/a?

Yes

No

If you are Hispanic or Latino/a, please specify:

Puerto Rican

Cuban

Mexican

Dominican

Other (specify)_____

What language do you speak at home or with family and friends?

English
Spanish
French
French Creole/Creole
Other (specify)_____

Section 3: This section is intended to gather information on adolescent/young adult patients and oral health & HIV

The treatment and management of adolescents living with HIV is within the scope and expertise of the general dentist

Agree
Disagree
Strongly agree
Strongly disagree

You are confident in your ability to deliver dental care for adolescents.

Agree
Disagree
Strongly agree
Strongly disagree

The treatment and management of adolescents living with HIV is within the scope and expertise of the pediatric dentist

Agree
Disagree
Strongly agree
Strongly disagree

You are confident in your ability to deliver dental care for adolescents living with HIV

Agree
Disagree
Strongly agree
Strongly disagree

An HIV infected person with no AIDS diagnosis is defined as an individual with: (Please select one)

HIV infection and CD4 lymphocyte count >500 cells/mm
HIV infection and CD4 lymphocyte count <500 cells/mm
HIV infection and CD4 lymphocyte count >200 cells/mm
HIV infection and CD4 lymphocyte count <200 cells/mm
HIV infection regardless of the CD4 lymphocyte count

Which is the most common oral infection seen in patients infected with HIV?

Kaposi 's Sarcoma
Candidiasis
Citomegalovirus infection
Apothous Ulcers
Human Papillomavirus

Plasma viral load can offer information about which of the following?

Degree of HIV viral replication

Degree of HIV infectiousness

Patient compliance with HIV medical treatments

Efficacy of Highly Active Antiretroviral Therapy

All of the above

Adolescents living with HIV are:
(Please select one answer for each statement)

	Agree	Strongly Agree	Disagree	Strongly Disagree
Frequently miss appointments	O	O	O	O
Know their HIV status	O	O	O	O
Report their HIV status	O	O	O	O
Complete their medical history questions honestly	O	O	O	O
Are welcome in my practice	O	O	O	O
Often have dental insurance	O	O	O	O
Are frequently fearful during dental visits	O	O	O	O

Thank you very much for your time.

We would like to send a gift card in the amount of $5. as a token of my appreciation of your participation.

Please send your name and address to: OHALWHA@gmail.com

Appendix E

OH YALWH

Professional Information Letter

Noreen Myers-Wright MA, RDH, CHES
Columbia University, Teachers College
Dept. Health & Behavioral Studies
Program of Health Education
nlm2119@tc.columbia.edu
212 342 1821

Dear

I am a doctoral candidate at Teachers College, Columbia University in the section of Health Education and a research coordinator at the College Dental Medicine, Columbia University.

My dissertation research focuses on the oral health needs of adolescent patients living with HIV. Part of my work includes gathering information from oral health professionals on their views on providing care for this population.

Five different dental professionals in New York State will be asked to participate in this research project, general practice dentists, pediatric dentists, advanced general dentistry residents, pediatric dentistry residents and registered dental hygienists.

I invite you to take a brief survey containing question items on your views of providing cultural competent care, HIV knowledge and the best-trained provider to care for this group of adolescents.

Your participation is completely voluntary and no personal identifying information will be asked or recorded. All responses will be reported in aggregate utilizing Qualtrics online survey support service. As a token of my appreciation for your participation, I am prepared to send each participant a $5.00 gift card.

Although your participation in this study is voluntary, your thoughts would enable a presentation of a well-rounded assessment of oral health providers. The information gathered from dental providers at multiple stages of professional development as well as scopes of practices, could support the development of better informed education modules for dental professionals.

By following the link provided you will be giving your consent to participate in this voluntary survey.

_____

I thank you for your time.

Sincerely,

Noreen Myers-Wright

Appendix F

Dental Staff Survey

Default Question Block

Todays Date:

I am conducting this survey to gather some information about your background to better describe the information I will be asking during the focus group.

The survey includes a total of 7 questions and it should take you no more than 5 minutes to complete.

Thank you for your cooperation

In what year were you born Year _ _ _ _

What is your gender?

Male
Female
Transgender

How would you describe your race/ethnicity?

Black or African American
Asian
American Indian or Alaska Native
Native Hawaiian or Pacific Islander
White (non-Hispanic)
Multiracial/Biracial (specify) _____
Hispanic
Other (specify) _____

How many years of school have you completed?

Elementary up to and including High School
Vocational School
College
Other (specify) _____

What language do you speak most of the time, with friends and family?

English
Spanish
French
Creole/French Creole
Other (specify) _____

Are you currently employed:

Full Time
Part Time
Other (specify) _____

How do you get to work?

Walk

Car

Bus

Van

Taxi

Subway

Appendix G

OH YALWH Dental Staff Focus Group Guide

Thank you for taking the time to speak with me today. I am conducting this study to gather information on dental staff's role in providing oral healthcare for 15- 24-year-old adolescents living with HIV.

For example, what is your role in helping adolescents keep their appointments, and helping them feel welcome during their visit to the dental clinic.

I will ask each participant complete a consent form acknowledging that they understand they are participating in a research study, what they will be asked to do and that participation is voluntary.

Has everyone completed the consent form?

At the end of this interview I would like to offer each person a $5.00 coffee gift card, and you are welcome to enjoy the refreshments we have here today.

Before we begin our discussion I would like to ask you to complete a brief background survey. The survey will not ask you any personal identifiable questions and should take no more than 5 minutes to complete.

If everyone agrees I would like to record our discussion using an MP3 recorder; this improves my ability to accurately record your comments. Only your first name will be used during our discussion and will be removed and replaced with codes on the transcription of the recording.

I am planning to interview 6-8 dental auxiliary staff from the dental clinic. The interview transcripts will remove any information that might identify you or your institution.

Introductions: I would like to ask each person introduce himself or herself using only their first name and stating what their role is in the dental clinic.

Let's begin:

1. Please describe the importance of your interactions with patients in your clinic.

2. Do you feel you play a key role when working with adolescents that are living with HIV?

3. What would you estimate is the percentages of the patients visiting your clinic are HIV+ (Probe: 100%, 75%, 50% 25%)

4. Do you think everyone that is HIV+ reports their status?

5. Are adolescents difficult patients to provide care for?

Why? Can you offer some examples?

6. What could members of the dental staff do to help adolescents living with HIV keep their appointments?

7. What could members of the dental staff do to help adolescents living with HIV feel welcome at your clinic?

8. Are adolescents fearful of seeing the dentist or hygienist?

Follow-up - would fear have something to do with their missed appointments?

9. Do you feel you receive appropriate training to provide care for diverse populations?

Prompt: ethnically, racially or LBGTQ patients.

10. If you could change anything about the care that your clinic offers adolescents living with HIV what would that be?

Is there anything else you would like to add about your role in your clinic and adolescent patients living with HIV? Do you have any questions?

Thank you very much for your time.