University of Nevada, Reno

Healthcare Utilization, Unmet Service Needs, and HIV Treatment Outcomes among People Living With HIV/AIDS in Nevada

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By
Xiangjun Zhang

Dr. Roy F. Oman, Dissertation Advisor

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requirements for the degree of

Advisor

Committee Member

Committee Member

Committee Member

Graduate School Representative

David W. Zeh, Ph.D., Dean
Graduate School

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Abstract

Comorbidity rates and service needs are high among people living with HIV/AIDS (PLWHA). The effects of service utilization and unmet service needs on HIV treatment outcomes are not well understood. Furthermore, health disparities among racial/ethnic groups exist across the stages of HIV care continuum. Racial/ethnic differences in service utilization and HIV treatment outcomes are also not well explored. The purpose of this dissertation is to use Andersen's Behavioral Model of Health Service Use (ABM) as a theoretical framework to conceptualize and explain the associations between service utilization, unmet service needs, and HIV treatment outcomes, as represented by antiretroviral therapy (ART) adherence and linkage to care, among PLWHA; and to investigate possible race/ethnicity differences in service utilization, unmet service needs, and HIV treatment outcomes. Multivariable logistic regression analyses were conducted to examine associations between service utilization, unmet service needs, and ART adherence and linkage to care. Significant race/ethnicity differences regarding service utilization, linkage to care and medication adherence were assessed using multiple linear regression and multiple logistic regression models. Using a sample of 177 PLWHA in Nevada, this dissertation demonstrated that unmet services needs were significantly negatively associated with ART adherence. No significant association was found between service utilization and linkage to care. However, participants who reported late linkage to care also reported needing more help obtaining health insurance and a greater need for support groups compared to participants who reported timely linkage to care. In addition, significant racial/ethnic differences were observed for seven individual services, including medical care, mental health care, case

management, HIV and health classes, financial help, help understanding medicines, and help filling out forms. Collectively, the findings contribute to the HIV healthcare service utilization literature by showing a direct association between unmet service needs and ART adherence. The results demonstrated that health disparities do exist among racial/ethnic groups in specific healthcare services. The results can inform interventions that aim to address specific service needs and improve healthcare services for certain racial/ethnic groups. Furthermore, the study informs programs and policies that allocate health services and deliver needed services to maximize the benefits of HIV care.

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Chapter 1

Chapter 1 Introduction and Overview of the Dissertation

The HIV Epidemic

Despite great advances in the prevention, diagnosis, and treatment in the last three decades, HIV remains a significant public health concern globally and in the U.S. There were an estimated 940,000 deaths due to HIV-related causes in 2017.[1] There are approximately 37.9 million people in the world living with HIV and 1.7 million of them were newly diagnosed cases in 2018.[2] However, only 23.3 million of these people are in antiretroviral therapy (ART).[2]

In 2016 an estimated 1.1 million people were living in the U.S. with HIV/AIDS, and approximately 14% of them did not have an HIV diagnosis, which means they are unaware of their HIV status.[3] In 2017, 38,739 people were newly diagnosed HIV positive which is a rate of 11.8 per 100,000 population.[1] In 2017, 15,807 people who were living with HIV/AIDs (PLWHA) died.[1] The rate of PLWHA receiving ART is estimated to be approximately 24% to 37%.[4-6] Although ART has been demonstrated to effectively extend life expectancy[7] and improve the quality of life,[8] the treatment outcome for PLWHA is still suboptimal.

Nevada's population ranks 33rd in the nation with an estimated 3.09 million residents in 2019.[9] However, the prevalence of HIV is greater than the national level. In 2016, the rate of PLWHA per 100,000 population in Nevada was 375 compared to 368 at the national level.[10,11] In addition, Nevada has a high rate of new-diagnosed HIV cases. It was ranked 6th in the nation with a rate of 20 new HIV infections per 100,000 population in 2017[10,12] compared to 14 new infections per 100,000 population at the national level.[11] In 2016, of the 9,194 PLWHA in Nevada, 43.0% were Caucasian, 25.4% Hispanic, and

24.5% African American.[10] The high HIV prevalence and high rate of new HIV diagnoses in Nevada are a call for more attention to HIV prevention and care, which could effectively decrease new infections in the population.

Furthermore, most of Nevada's population is concentrated in three urban counties. The remaining 14 rural and frontier counties of Nevada comprise 87% of the state's land mass but only 9.7% of Nevada's population.[13] The geographic distribution of Nevada's population is one challenge to delivering quality health care services especially in rural communities, and therefore unmet service needs may be particularly high in rural areas.

HIV Care Continuum

The HIV care continuum was introduced to demonstrate the whole spectrum of HIV prevention and care.[4] It includes HIV testing, diagnosis, linkage to care, retention in care, and receipt and adherence to ART.[14] The achievement of HIV viral suppression depends on successfully overcoming barriers that exist in each stage of the HIV care continuum. The HIV care continuum has been used to closely examine the proportions of PLWHA engaged in each stage along the spectrum, identifying where the drop-outs occur to improve services, and achieving the goal of viral suppression.[15] The 2020 National HIV/AIDS Strategy (NHAS) is a five-year plan that sets priorities and targets for HIV prevention and care in the U.S.[16] It has three primary goals: reducing new infections, increasing access to HIV care and optimizing health outcomes, and reducing HIV health disparities.[16]

Multiple indicators have been used to assess and evaluate HIV treatment outcomes.[17] One indicator is HIV viral suppression, which is the optimal HIV treatment

outcome. PLWHA with continued viral suppression could remain healthy as indicated by an undetectable viral load and a reduced risk of transmission.[18] Data from the Centers for Disease Control and Prevention (CDC) show that in 2011 only 30% of 1.1 million PLWHA in the U.S. have reached viral suppression.[5,6] Another indicator is CD4 cell count. The CD4 count usually deceases in response to HIV infection and the progression of HIV disease, and increases in response to effective ART. People with very low CD4 count are more susceptible to specific opportunistic infections.[1]

Behavioral-based HIV outcomes include linkage to care, medication adherence, and retention or engagement in HIV care. Linkage to care refers to the period from an individual receiving an HIV positive diagnosis to visiting an HIV doctor or initiation of medical treatment, which commonly requires daily doses of ART medications.[15,17] Furthermore, PLWHA must visit HIV clinics regularly after they start HIV treatment.

ART is a combination of multiple antiretroviral drugs used to suppress HIV and stop the progression of HIV disease.[1] ART adherence is defined as how well an individual adheres to the medication regimen as prescribe. ART has demonstrated effectiveness in preventing HIV transmission and reducing rates of HIV-related death.[18,19] The World Health Organization (WHO) has recommended ART for all people with HIV soon after diagnosis regardless of the stage of the disease and CD4 count,[20] which measures the number of CD4 T lymphocytes in a sample of blood and indicates the health of the immune system.[21] CD4 count is an important indicator for PLWHA and is used to predict HIV progression and to monitor the immune system's response to ART.[21]

Retention and engagement in HIV care were included in this study to measure how well an individual engages in HIV treatment and care related activities, such as clinic visits and lab tests.[22] These indicators have established associations with HIV treatment outcomes and they are potential intervention targets. Early linkage to care is associated with early initiation of medication and could shorten the time to viral suppression.[23] ART adherence and retention in care are consistently associated with better clinical and health outcomes, including increased CD4 counts,[24] viral suppression,[25,26] and survival.[27] In addition, retaining patients in HIV care could reduce health care costs.[28]

Service Utilization among PLWHA

In addition to HIV care, PLWHA may have other medical care needs for their comorbid conditions or diseases, such as mental disorders, substance abuse disorder, heart diseases, etc. The services are labeled medical services. Furthermore, services that provide support for PLWHA have been widely adopted to improve retention and engagement in HIV care.[29] These support services include case management, financial support, transportation, housing, etc.[29]

Lack of access to needed services is a barrier to HIV care and it is associated with negative HIV health related outcomes, such as retention in HIV care,[30] ART adherence,[31] and viral suppression.[32] The Ryan White HIV/AIDS program (RWHAP) is a federally-funded program that funds states and metropolitan areas to increase medical and support services for low-income, uninsured and underinsured PLWHA.[33] Other insurance programs, such as Medicaid, only provide medical support.[34] Low-income PLWHA who

receive care through a RWHAP-funded facility or receive support from RWHAP are more likely to be prescribed ART and to achieve viral suppression.[32,35] Therefore, support service is a necessary core component in HIV care to achieve optimal treatment outcomes.

In addition, disparities exist between racial/ethnic groups in terms of access to quality health care services and health outcomes.[36] Little is known about associations between medical and support service utilization and HIV health-related outcomes and the differences of service utilization among racial/ethnic groups in racially diverse communities. The findings of this study therefore could be used to improve medical and support services to achieve better HIV-related health outcomes.

Theoretical Framework

Andersen's Behavioral Model of Health Service Use (ABM) provides a theoretical framework to understand how healthcare services and other factors influence health behaviors and outcomes.[37] The theory has been applied to PLWHA.[38,39] The model includes patient factors, healthcare environmental factors, and other environmental factors that influence health outcomes (e.g., medication adherence and retention in care) and underscore the impact of health services utilization on health outcomes.[37,39] According to the ABM, enabling patient factors are the resources that encourage patients' healthcare-associated behaviors. The healthcare environment comprises services that are available for patients and that also includes clinic and provider factors.[37]

The ABM has been used to explain how enabling patient factors and healthcare services are associated with health outcomes in HIV care context.[38,39] Based on the ABM,

enabling factors are commonly called support services in HIV care, such as transportation, financial help, and child care and housing which facilitate PLWHA engaging in HIV care.[37,39] Healthcare services are ancillary services or medical services, such as medical care, pharmacy, and mental health care, in addition to HIV care.[39] According to the ABM, both medical services and support services substantially influence patients' health behaviors and health outcomes. Medical and support service utilization in the HIV care context will also be assessed in this study. The enabling patient factor refers to support services in the HIV care context and healthcare service refers to medical services in the HIV care context. According to the ABM, both medical and support services utilization affect patients' health outcomes. Other theory-informed outcome variables in this study are ART adherence and linkage to care, which are essential health outcomes of PLWHA (Figure 1).
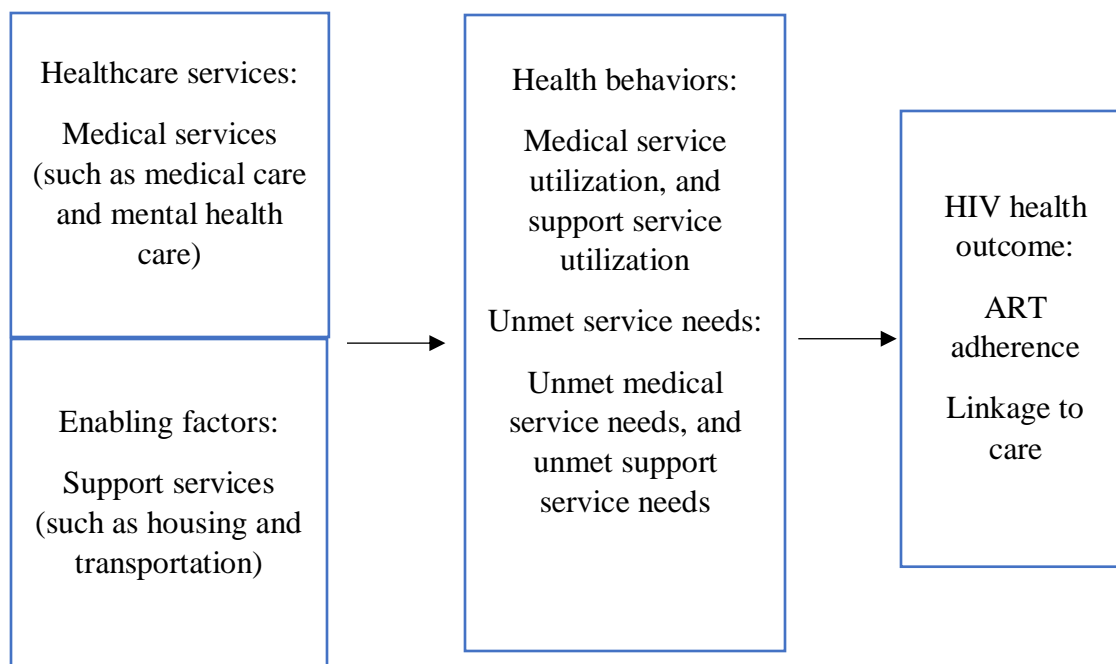
Figure 1. Andersen's Behavioral Model of Health Service Use as a framework for explaining the HIV care context.

Review of Selected Research

ART adherence is a key component for PLWHA to obtain the full benefits of ART and achieve viral suppression.[40] Improving adherence is vital to achieving the goals of the National HIV/AIDS Strategy that aim to reduce new infections and improve health outcomes.[16] PLWHA who stay in HIV care require regular clinical visits, laboratory tests, ART medication prescriptions, and ART monitoring from their healthcare providers. ART successfully reduces HIV-related mortality and improves health and prolongs life.[41-43] As a result, the proportion of non-HIV related mortality for PLWHA has increased.[44,45] From 2000 to 2011, the mortality rate for both HIV conditions (26.4 to 8.3 per 1,000 person-years among PLWHA) and non-HIV conditions (from 10.5 to 7.6 per 1,000

person-years among PLWHA) decreased; however, the mortality rate for non-HIV conditions increased from 25% to 48% among PLWHA.[45]

Linkage to care is defined as the period from documented HIV diagnosis to visiting an HIV care provider or initiation of medical treatment.[15,17] Linkage to care is the starting point of engagement in HIV care for those who are newly diagnosed with HIV. In 2016, the recommended time for linkage to care was reduced to less than one month in contrast to the previous 3-month recommendation.[46] Linkage to care, as an indicator of the HIV care continuum, is associated with other HIV treatment outcomes. It facilitates early initiation of HIV treatment and reduces time to viral suppression.[47] Early linkage to care is associated with early initiation of ART, which in turn, is associated with reduced morbidity, mortality, and HIV transmission.[48,49]

Linkage to care is also an indicator of the overall quality of healthcare system. Most healthcare institutes create patients' records during the patient's first visit and also provide them with needed support for HIV care, such as case management, financial support, and medical assistance.[50] The quality of the linkage to care for PLWHA is related to the individuals' utilization of HIV care services. For example, some structural-level barriers could impede timely linkage to care.[51] These barriers include health care system factors such as a lack of patient navigation assistance and long appointment waiting times, as well as social factors, such as HIV stigma.[51] These factors also have been identified as barriers to HIV healthcare services.[39,52] Furthermore, interventions to improve linkage to care and HIV care utilization have used similar strategies such as health education, motivational counseling, and appointment assistance (e.g. peer accompany) and coordination.[53]

HIV disproportionately affects some racial/ethnic groups in the U.S. African Americans have the highest proportion of individuals living with HIV/AIDS, as well as the highest number of annual new diagnosed HIV cases. African Americans account for an estimated 41.7% of the 1.1 million PLWHA despite representing only approximately 13% of the U.S. population.[54] From 2010 to 2017 U.S. HIV diagnoses for African Americans decreased by15%; however, of 37,832 new HIV diagnoses in 2018, 42% were African Americans.[55] Hispanics are also disproportionately affected by HIV. Although the Hispanic population makes up only 18% of the U.S. population it accounted for 22% of all PLWHA and 27% of newly diagnosed HIV cases in 2016.[54,56]

The cumulative effects of ART medications and HIV inflammation can lead to complications, such as cardiovascular disease, lymphoma and osteoporosis, and other adverse health outcomes. The prevalence of chronic disease and conditions among PLWHA is higher compared to the general population and it increases with age. A large cohort study found that more than 90% of PLWHA are diagnosed with at least one chronic condition compared to nearly 50% in the general population.[57,58] Nearly 80% of the cohort reported at least 2 conditions and more than 20% reported more than 4 conditions, compared to 14% reporting 2 conditions and 12% reporting 3 or more conditions in the general population.[57,58] The proportion of chronic disease and conditions among older PLWHA is even higher with as much as 94% of PLWHA aged 50 years or older having at least one chronic disease or condition.[59] PLWHA now have a longer life expectancy and comorbidities are therefore increasing. As a result, HIV care shifts to a chronic disease model and ancillary care and support services become essential for PLWHA if they are to receive the full benefits of healthcare treatment.[60,61]

Previous studies examining relationships between support services utilization and HIV treatment outcomes have been limited in that the majority investigated individual services. For example, one study found that a case management system that navigates patients to services in the healthcare system was able to improve treatment adherence.[62,63] Another study found that unstable housing for PLWHA was a barrier to HIV medication access and ART treatment.[64] In a qualitative study, lack of transportation was identified as an important barrier to service utilization and ART adherence among PLWHA.[65,66] These studies suggested that providing support services (e.g., housing and transportation support) could contribute to improved HIV treatment outcomes.[64-66]

Research focusing on medical care and services has also been limited to the investigation of individual services. For example, mental health and substance abuse treatment services are the most frequently investigated services in HIV care likely because of the high prevalence and negative impact of mental illnesses and substance abuse on HIV treatment outcomes.[67-71] In addition, few studies have investigated the needs of PLWHA for non-HIV medical care services (such as dental, eye, and vision care). Three studies have reported the percentages of PLWHA with unmet service needs and found that unmet medical service needs were higher than unmet support service needs.[72-74] However, the studies did not investigate possible associations between multiple medical services and HIV treatment outcomes.

Furthermore, because comorbidity rates are high among PLWHA, they may need more than one medical service in addition to HIV care. To my knowledge, only one published study has investigated multiple types of unmet service needs and their possible association with ART adherence.[75] The study investigated associations between 7 series

of unmet service needs (including housing support, emergency provisions, support group, mental health services, legal services, nutrition, and financial assistance and benefits) and taking any HIV medication and medication adherence.[75] The study used a cross-sectional design and surveyed 526 participants from multiple HIV clinics in southeastern U.S.[75] The study found that participants with unmet service needs were less likely to currently be in ART treatment compared to participants who did not report unmet service needs.[75] However, the study only included a limited number of services and did not include utilized services.[75]

Furthermore, although previous studies have identified factors associated with linkage to care and service utilization,[39,52] no studies have reported finding a direct association between linkage to care and service utilization. Moreover, previous studies that investigated service utilization did not distinguish between medical and support services,[75] which are two very different components in HIV care that might influence linkage to care differently.

The considerable variation in healthcare utilization by race/ethnicity may also have an impact on health disparities among racial groups. Stigma, inadequate access to culturally competent services, deficiency of services, and limited services are common structural-level barriers to HIV care access for racial/ethnic minorities.[76] For example, African Americans are more likely to live in areas that lack healthcare services or that have poorer quality healthcare.[77] Language can also act as a barrier to access to healthcare among people who do not speak English.[78] Racial/ethnic minorities are also more likely to be uninsured or underinsured.[79] In addition, race-based discrimination is

not only associated with negative mental health, HIV health outcomes and HIV care satisfaction,[80] it is also associated with a lower likelihood of service utilization.[81]

Research focusing on race/ethnicity disparities and service utilization in HIV medical care and treatment is limited. One study reported that approximately one-fourth of Hispanics had an unmet need for non-HIV medical services, such as dental and vision care.[72] The unmet needs for support services, such as care management, and food or nutrition are also high among Hispanic PLWHA.[73]

In summary, medical and support services are essential for PLWHA in addition to HIV care. The literature suggests that some individual services (e.g. case management, patient navigation assistance) are associated with HIV treatment outcomes (e.g. ART adherence).[62,63] The relationship between multiple services and HIV treatment outcomes is none-the-less unclear. Furthermore, race/ethnicity health disparities are present in the stages of the HIV care continuum. However, potential between-group (race/ethnicity) differences regarding HIV service utilization have not been well explored.

Research Hypotheses

This study includes a comprehensive list of support services and medical services with the goal of investigating associations between service utilization and unmet service needs and ART adherence and linkage to care. This study also explores differences in medical and support service utilization, unmet service needs, ART adherence, and linkage to care among racial/ethnic groups. Based on the literature, the hypotheses of the study are that:

1. Medical and support service utilization are positively associated with ART adherence.

2. Unmet medical and support service needs are negatively associated with ART adherence.

3. Medical and support service utilization are positively associated with timely linkage to care.

4. Unmet medical and support service needs are negatively associated with timely linkage to care.

5. There are racial/ethnic differences regarding medical and support service utilization, and unmet service needs.

6. There are racial/ethnic differences regarding ART adherence and linkage to care.

Methodology

Participants

The study participants (N=177) were obtained from a statewide needs assessment project. This project was designed to identify HIV prevention and care service needs in Nevada with the goal of developing an Integrated HIV Prevention and Care Plan.

Participants were recruited from a variety of provider locations and community organizations through flyers, social media, and word of mouth between January and March 2016. The researchers sent a letter to request assistance for recruiting participants of the survey. The letter was sent to HIV clinics, community organizations, and the Department of Health and Human Services (HHS) in Nevada. Specific clinics and

community organizations that received the letter included Northern Nevada HOPES (NNHOPES), Community Outreach Medical Center, Wellness Center of University Medical Center (UMC Wellness), Aid for AIDS of Nevada (AFAN), Network Statewide Offices, and Access to Healthcare Network (Reno AHN). The letter also included a website link for participants to complete the online version of the survey.

The inclusion criteria were participants aged 18 and older and currently living with HIV/AIDS. The sample included newly diagnosed patients, patients who were retained in HIV care for a period of time, and Ryan White clients receiving HIV care.

Participants completed a self-administered questionnaire on paper in HIV clinics or online (Appendix A). The survey was anonymous and took an average of 20 minutes to complete. The survey included questions that assessed sociodemographic factors, HIV disease status, service utilization, reasons for not getting services, linkage to care, and ART adherence. All surveys and recruitment flyers were provided in both English and Spanish. Participants received $10 gift cards for their participation.

Measures

The main variables included: ART adherence, linkage to care, service utilization, unmet service needs, and the participants' race/ethnicity.

ART adherence was measured by the participants' response to the question: "Have you ever stopped taking your HIV medicines in the last two years?" Possible responses were "yes" or "no."

Linkage to care was measured by the participants' response to the question: "After you were diagnosed with HIV, how long did it take before you first saw a doctor?"

The survey provided seven options with time frames. The variable was categorized into two levels based on the CDC's criterion: timely linkage to care (participants were linked to care less than one month after receiving an HIV diagnosis) and late linkage to care (participants were linked to care more than one month after receiving an HIV diagnosis).[17]

The service utilization question asked participants to check all the services they were using or have used in the current year. The unmet service needs question asked participants to check all the services that they needed but did not get. For both questions, participants chose from twenty-four services that were categorized into ten medical services and fourteen support services. Examples of medical services were medical care, specialty doctors and dental care. Examples of support services were transportation, help filling out forms and child care. Service utilization and unmet service needs were coded as continuous variables.

For the race/ethnicity variable, the survey provided seven possible responses which were coded into four groups: black or African American, Hispanic or Latino/a, white or Caucasian and other. The "other" group included American Indian or Alaskan Native, Native Hawaiian or Pacific Islander, Asian, and multi-racial participants.

The most-cited unmet service needs and reasons that participants did not receive needed services were reported. Reasons for late linkage to care were also reported. The proportion of that participants with problems getting into the doctor's office after receiving an HIV diagnosis and the proportion of participants who received all services they needed were also reported.

Other sociodemographic variables included age, gender, and sexual orientation. The number of years of HIV infection was also included because previous studies found that duration of HIV infection was associated with comorbidity, which may in turn be related to service needs.[82]

Statistical analyses

H1. Medical and support service utilization are positively associated with ART adherence.

H2. Unmet medical and support service needs are negatively associated with ART adherence.

To investigate hypotheses 1 and 2, descriptive analyses were conducted to assess potential differences by sociodemographic characteristics, number of years of HIV infection, and medical and support services utilization based on ART adherence status. Bivariate analyses were conducted using Chi-square tests, independent sample t-tests, and Fisher's exact tests. A series of multivariable logistic regression analyses were conducted to assess the associations between used medical services, used support services, unmet medical service needs, and unmet support service needs with ART adherence.

H3. Medical and support service utilization are positively associated with timely linkage to care.

H4. Unmet medical and support service needs are negatively associated with timely linkage to care.

To investigate hypotheses 3 and 4, Chi-square tests, independent sample t-tests, and Fisher's exact tests were conducted to assess possible between-group differences (timely- or late-linkage to care) regarding sociodemographic characteristics, number of years of HIV infection, overall services utilization, overall unmet service needs, and individual service utilization and unmet service needs. Multivariable logistic regression models were conducted to assess associations between service utilization, unmet service needs, and linkage to care.

Previous studies reported differences in ART adherence and linkage to care among different sociodemographic groups.[83,84] Therefore, in order to eliminate the influence of sociodemographic characteristics, sociodemographic variables, including age, gender, and race/ethnicity, were controlled in the model. The number of years of HIV infection was also controlled because research has shown that it has an indirect association with participants' service needs.[82]

H5. There are racial/ethnic differences regarding medical and support service utilization, and unmet service needs.

H6. There are racial/ethnic differences regarding ART adherence and linkage to care.

To investigate hypotheses 5 and 6, the sample was stratified into the four race/ethnicity groups. One-way ANOVA, Chi-square tests and Fisher's exact tests were conducted to assess possible between-group differences (race/ethnicity) regarding sociodemographic factors and years of HIV infections. Multiple logistic regression models were conducted to assess possible between-group differences regarding HIV treatment outcomes. Multiple linear regression was conducted to assess possible

between-group differences regarding utilized services and unmet service needs. For individual utilized and unmet service needs, multiple logistic regression was conducted to assess possible between-group differences. Only the individual services of the twenty-four services that showed significant between-group differences were reported. The appendices include the survey which has the complete list of individual services (Appendices A and B). Finally, the proportion of PLWHA who had no issues with linkage to care by race/ethnicity and the proportion of PLWHA who have received all needed services were also reported. Sexual orientation and number of years of HIV infection were controlled in all regression models. SAS 9.4 (Cary, NC) was used to conduct all analyses.

Chapter 2 Healthcare Utilization, Unmet Service Needs,

and Medication Adherence

Introduction

Antiretroviral therapy (ART) has significantly decreased HIV-associated morbidity and mortality and prevented new infections.[85-87] However, a large proportion of people living with HIV/AIDS (PLWHA) are unable to achieve viral suppression, defined as an undetectable viral load, which would allow them to remain healthy and prevent transmission to others.[18] In the U.S., only 30% of total estimated PLWHA achieve viral suppression.[5] After receiving an HIV diagnosis, PLWHA must take ART medication daily to suppress the virus for the remainder of their lives. ART adherence is therefore a key component for PLWHA to obtain the full benefits of ART and achieve viral suppression.[40] Improving adherence is vital in achieving the goals of the National HIV/AIDS Strategy that aim to reduce new infections and improve health outcomes.[16]

PLWHA who stay in HIV care require regular clinical visits, laboratory tests, ART medication prescriptions, and ART monitoring from their healthcare providers. ART successfully reduces HIV-related mortality and improves health and prolongs life.[41-43] As a result, the proportion of non-HIV related mortality for PLWHA has increased.[44,45] From 2000 to 2011, the mortality rate for both HIV conditions (26.4 to 8.3 per 1,000 person-years among PLWHA) and non-HIV conditions (from 10.5 to 7.6 per 1,000 person-years among PLWHA) decreased; however, the mortality rate for non-HIV conditions increased from 25% to 48% among PLWHA.[45]

Furthermore, the cumulative effects of ART medications and HIV inflammation lead to complications, such as cardiovascular disease, lymphoma and osteoporosis, and

other adverse health outcomes. The prevalence of chronic disease and conditions among PLWHA is higher compared to the general population and increases with age. A large cohort study found that more than 90% of PLWHA are diagnosed with at least one chronic condition compared to nearly 50% in the general population.[57,58] Nearly 80% of the cohort reported at least 2 conditions and more than 20% reported more than 4 conditions, compared to 14% reporting 2 conditions and 12% reporting 3 or more conditions in the general population.[57,58] The proportion of chronic disease and conditions among older PLWHA is even higher.[59] At a time when PLWHA have a longer life expectancy, comorbidities are increasing and HIV care shifts to a chronic disease model, ancillary care and support services are essential for PLWHA to receive the full benefits of healthcare treatment.[60,61]

Previous studies examining relationships between support services utilization and HIV treatment outcomes have been limited in that the majority investigated individual services. For example, one study found that a case management system that navigates patients to services in the healthcare system was able to improve treatment adherence.[62,63] Another study found that unstable housing for PLWHA was a barrier to HIV medication access and ART treatment.[64] In a qualitative study, transportation was identified as an important barrier to service utilization and ART adherence among PLWHA.[65,66]

Research focusing on medical care and services has also been limited to the investigation of individual services. For example, mental health and substance abuse treatment services are the most frequently investigated services in HIV care taking into account the high prevalence and negative impacts of mental illnesses and substance abuse on HIV treatment outcomes.[67-71] In addition, few studies have investigated the needs of

PLWHA for non-HIV medical care services (such as dental, eye and vision care). Three studies have reported the percentages of PLWHA with unmet service needs and found that unmet medical service needs were higher than unmet support service needs.[72,73,74] However, the studies did not investigate possible associations between multiple medical services and HIV treatment outcomes.

Furthermore, comorbidity rates are high among PLWHA; therefore, they may need more than one medical service in addition to HIV care. To our knowledge, only one published study has investigated multiple types of unmet service needs and the association with ART adherence.[75] The study found that participants with unmet service needs were less likely to currently be in ART treatment compared to participants who did not report unmet service needs.[75] However, the study included only a few health services and had measurement limitations.[75]

The present study includes a comprehensive list of both support services and medical services with the goal of investigating associations between service utilization and unmet service needs with ART adherence. Specifically, the hypotheses are that: 1) medical and support service utilization are positively associated with ART adherence; and 2) unmet medical and support service needs are negatively associated with ART adherence. The results of the study could be used to inform health promotion programs designed to deliver needed services and to allocate health services to maximize the benefits of HIV care.

Methods

Participants

Study participants (N =177) were obtained from a Nevada statewide health service needs assessment survey. The purpose of the project was to identify HIV prevention and care service needs in Nevada with the goal of developing and implementing an Integrated HIV Prevention and Care Plan.

Between January and March 2016, PLWHA were recruited from a variety of provider locations and community organizations through flyers, social media, and word of mouth. A letter from the project researchers requesting assistance with recruiting participants for the survey was sent to HIV clinics, community organizations and the Department of Health and Human Services in Nevada. The inclusion criteria were participants aged 18 and older and currently living with HIV/AIDS. The sample included newly diagnosed patients, patients who were retained in HIV care for a period of time and Ryan White clients receiving HIV care. In addition, the analyses were limited to participants who answered "yes or no" to the ART adherence question "Have you ever stopped taking your HIV medicines in the last two years?" Respondents who did not answer this question (n=10) or who never started HIV medication treatment (n=5) were excluded from the study. A total of 162 participants were included in the analyses.

The survey was anonymous and took an average of 20 minutes to complete. Participants completed a self-administered questionnaire on paper in HIV clinics or online. The survey included questions that assessed sociodemographic factors, HIV disease status, service utilization, reasons for not getting services, linkage to care, and ART adherence. The survey was provided in both English and Spanish. Participants received a $10 gift card for completing the survey.

Measures

The outcome variable was ART adherence, which was measured by the participants' response to the question: "Have you ever stopped taking your HIV medicines in the last two years?" Possible responses were "yes" or "no."

The independent variables were service utilization and unmet service needs. The service utilization question asked participants to "Please check all the services you are using now or have used this year." Participants selected from twenty-four services, such as mental health care, dental care, help getting food and case management, *etc*.

The unmet service needs question directed participants to "Please check all the services you need that you do not get." Participants selected from twenty-four services that were categorized into unmet medical service needs and unmet support service needs. There were ten medical services and fourteen support services listed in the survey for both service utilization and unmet service needs. Medical services and support services were coded as continuous variables.

The frequencies and proportions of the top three unmet service needs and self-reported reasons that participants did not receive their needed services were reported in order to provide more information for future interventions that aim to improve healthcare services and expand needed services for PLWHA. The survey included a list of fourteen reasons for "Why don't you get them?" Based on the nature of the reason, we categorized the reasons into two groups: service reason and other reason. An example of the service reason is "Services cost too much." An example of the other reason is "I didn't want anyone to know I was HIV positive." Participants could select multiple reasons from the fourteen reasons listed in the survey.

Sociodemographic variables included age, gender, sexual orientation and race/ethnicity. The number of years of HIV infection was also included because previous studies found that duration of HIV infection was associated with comorbidity, which may in turn be related to service needs.[82]

Statistical analyses

Descriptive analyses were conducted to assess potential differences among sociodemographic characteristics, number of years of HIV infection, and medical and support services utilization based on ART adherence status. Bivariate analyses were conducted using Chi-square tests, independent sample *t*-tests, and Fisher's exact tests.

A series of multivariable logistic regression analyses were conducted to assess the associations between used medical services, used support services, unmet medical service needs and unmet support service needs as the independent variables with ART adherence as the dependent variable. Previous studies reported differences in terms of access to medication and ART adherence status among different sociodemographic groups.[84,88] Therefore, in order to eliminate the influence of sociodemographic characteristics, sociodemographic variables in the model were controlled, including age, gender, and race/ethnicity. Duration of HIV infection also was statistically controlled because it was associated with ART adherence in previous studies.[89] All analyses were performed in SAS 9.4 (Cary, NC).

Results

Sample characteristics

Fifty (30.9%) participants reported having ever stopped taking their HIV medicines in the past two years. There were no significant differences between participants who reported ART adherence and non-adherence in regard to age, gender, sexual orientation, race/ethnicity, or number of years of HIV infection. ART adherence and non-adherence groups were not significantly different in regard to how many medical services (p=0.51, Table 1) and support services (p=0.18) they used in the past year. However, the ART non-adherence group showed significantly higher unmet medical service needs compared to the ART adherence group (p=0.007). There were no significant between-group differences in regard to unmet support service needs (p=0.09).

Table 1. Participant (N=162) characteristics and service utilization by ART adherence in the past two years.

Characteristics	Total (Column %)	ART adherence (112, 69.1 %, row %)	ART non-adherence (50, 30.9 %, row %)	P-value*
Age- continuous (mean, SD, years)	45 (11.7)	46 (11.5)	42 (12.0)	0.06§
Gender				0.28
Male	112 (71.8)	74 (66.1)	38 (33.9)	
Female	44 (28.2)	33 (75.0)	11 (25.0)	
Sexual orientation				0.87
Heterosexual	50 (30.9)	35 (70.0)	15 (30.0)	
Homosexual	83 (51.2)	56 (67.5)	27 (32.5)	
Other	29 (17.9)	21 (72.4)	8 (27.6)	
Race/ethnicity				0.23#
White, not Hispanic	55 (34.3)	35 (63.4)	20 (36.4)	
Black, not Hispanic	43 (26.9)	30 (69.8)	13 (30.2)	
Hispanic	35 (21.9)	23 (65.7)	12 (34.3)	
Other/unknown	27 (16.9)	23 (85.2)	4 (14.8)	
Number of years HIV infected -continuous (mean, SD, years)	13 (10.6)	14 (10.9)	12 (9.8)	0.56§
Used services this year				
Medical services (mean, SD, range 0-10)	2.5 (1.9)	2.6 (1.9)	2.4 (2.0)	0.51§
Support services (mean, SD, range 0-14)	2.7 (2.2)	2.5 (2.0)	3.0 (2.5)	0.18§
Unmet service needs				
Medical services (mean, SD, range 0-10)	1.1 (1.6)	0.8 (1.1)	1.7 (2.2)	**0.007**§
Support services (mean, SD, range 0-14)	0.7 (1.2)	0.6 (1.0)	1.0 (1.5)	0.09§

SD= standard deviation

ART= antiretroviral therapy

*Comparisons made using Chi-square test

§ Comparisons made using Two sample t-test

Comparison made using Fisher's exact test

Service utilization and unmet service needs

In general, utilization of medical services (Mean = 2.5) and support services (Mean = 2.7) were low. The participants also reported a low number of unmet medical service needs (Mean = 1.1) and unmet support service needs (Mean = 0.7, Table 1). However, analyses (Table 2) indicated that participants with higher unmet medical service needs had higher odds of not adhering to ART (Adjusted Odds Ratio (AOR) = 0.69, CI 0.53-0.90) in the past two years. Participants with more support service needs also had higher odds of not adhering to ART (AOR = 0.68, CI 0.48-0.97).

Table 2. Associations between used services, unmet service needs and ART adherence among 162 participants.

Services	ART adherence		
	OR (95% CI)	AOR* (95% CI)	P-value
Used services			
Medical services	1.06 (0.89-1.27)	1.06 (0.87-1.30)	0.56
Support services	0.89 (0.76-1.04)	0.88 (0.74-1.04)	0.13
Unmet service needs			
Medical services	**0.69 (0.55-0.87)**	**0.69 (0.53-0.90)**	**0.006**
Support services	0.77 (0.58-1.01)	**0.68 (0.48-0.97)**	**0.033**

ART= antiretroviral therapy
OR= odds ratio
AOR= adjusted odds ratio
*Adjusted for age, gender, race/ethnicity and years after diagnosis

Only 12 (7.5%) of the 162 participants reported they had received all of the services they needed. The most needed medical services were vision care, dental care, and specialty doctors, and the most needed support services were financial help,

transportation, and food (Table 3). In addition, the most-cited reasons for not receiving services were services not covered by insurance, high cost, ineligibility, lack of information about services, and transportation and time inconvenience (Table 4).

Table 3. Participant (N=162) most-cited unmet medical and support service needs.

Unmet medical service needs (Frequency, %)		
Top 1	Vision care	42 (26.1)
Top 2	Dental care	41 (25.5)
Top 3	Specialty doctors	18 (11.3)
Unmet support service needs (Frequency, %)		
Top 1	Financial help	25 (15.7)
Top 2	Transportation	19 (12.0)
Top 3	Help getting food	12 (7.6)

Table 4. Participant (N=162) reasons for not getting services.

Why don't you get them?	Frequency, %
I get all the services I need	12 (7.5)
Service reason	
1. Services not covered by insurance.	29 (18.0)
2. Services cost too much.	17 (10.6)
3. I don't qualify for the services.	15 (9.4)
Other reason	
1. I don't know where to go.	38 (23.9)
2. I don't have transportation.	11 (6.9)
3. It takes too much time.	7 (4.4)

Discussion

The purpose of this study was to investigate associations among PLWHA's service utilization, unmet service needs, and ART adherence. The results indicated that participants with increased unmet service needs were less likely to adhere to their ART medications. The results are consistent with previous studies that found that individual unmet service needs are associated with ART adherence and HIV outcomes, such as housing, dental care and mental health services.[75,90]

The results also indicated that the participants' ART adherence was negatively associated with the amount of unmet support service needs, but that it was not associated with current utilized services. Previous studies have reported that food insecurity and housing instability were associated with poor ART adherence, unsuppressed viral load and less access to care. [91-94] However, perhaps other potential factors, such as the individuals' specific needs, health status, and comorbidity status that might be associated with the current service utilization, muted potential associations between utilized services and ART adherence.

Although the means for utilization and unmet needs were both generally low, a majority of the participants (92.5%) reported they did not receive all services they needed. Taking into account the association between unmet service needs and ART adherence, programs that focus efforts on improving service utilization and removing barriers to the access of needed services will contribute to the improvement of HIV outcomes, such as ART adherence. Service utilization, including support service and medical service, are vital to achieve the optimal treatment goals of ART adherence for PLWHA.

HIV disproportionately affects people living in poverty.[95] Further, because PLWHA are living longer and thus their comorbidities rates are also increasing, their need for comprehensive care are also increasing. However, at the same time basic needs are a prominent concern among PLWHA.[96] These factors create challenges to meeting the service needs of PLWHA. Although the Ryan White program has been providing medical and support services for a large number of PLWHA,[97] it is possible that service coverage gaps exist. More funding must be provided to deliver free or low-cost services for PLWHA. Health care practice and health promotion programming for PLWHA can also be informed by examining the reasons that the participants offered for not obtaining services.

Reasons for not obtaining services included lack of insurance coverage and factors related to cost and eligibility for the services. In addition, nearly one fourth of the participants reported they did not know where to go to receive services. Health promotion programming should focus not only on introducing new services at the community level, but also work to optimize the availability and awareness of current services. In addition, health promotion and policy advocacy efforts can focus on expanding as well as explaining health insurance coverage, reducing individuals' financial burden, disseminating information about service resources, and filling gaps in support services such as improving navigation in HIV care facilities and facilitating transportation.

Patient-centered services would be helpful if they became more oriented toward making services more accessible, feasible and convenient. Previous research examining integrated HIV care suggested some strategies that could be used to address service needs

of PLWHA. These strategies included enhancing collaboration and service integration, such as co-locating services, partnering to leverage resources, and staff cross-training.[98]

The study had limitations. First, the cross-sectional study design limits the ability to infer causal relationships. A longitudinal study design could assess the prospective impact of unmet service needs on long-term disease consequences and therefore provide more compelling information for designing interventions. In addition, the measure of medication adherence was dichotomous, which determined only if participants had ever stopped taking medication. An instrument that more fully measures the quantity of adherence (how many doses participants missed in a certain period) could be used to assess levels of adherence which would also permit a more in-depth comparison of the results to previous studies.

Conclusion

In summary, the study investigated relationships between a wide- range of service utilization and unmet service needs with ART adherence. The study included both medical and support services, utilized services and unmet service needs, and almost all services in the HIV care context. The results could inform health promotion programs that aim to alleviate service needs among PLWHA.

Chapter 3 Healthcare Utilization, Unmet Service Needs,

and Linkage to Care

Introduction

Linkage to care is defined as the period from documented HIV diagnosis to visiting an HIV care provider or initiation of medical treatment.[15,17] It is the starting point of engagement in HIV care for those who are newly diagnosed with HIV. In 2016, the recommended time for linkage to care was reduced to less than one month in contrast to the previous 3-month recommendation.[46] The goals of the U.S. National HIV/AIDS Strategy include increasing access to care and improving health outcomes for people living with HIV/AIDS (PLWHA).[16] The most recent (2020) objective for linkage to care is to have more than 85% of people who receive an HIV diagnosis linked to HIV care within one month.[16]

Linkage to care, as an indicator of the HIV care continuum, is associated with a variety of other HIV treatment outcomes. It facilitates early initiation of HIV treatment and reduces time to viral suppression.[47] Early linkage to care also is associated with early initiation of antiretroviral therapy (ART), which in turn is associated with reduced morbidity, mortality, and HIV transmission.[48,49] However, current linkage to care rates are suboptimal, with an estimated 78% or fewer PLWHA linked to care within one month of receiving an HIV diagnosis.[4,15,17]

Linkage to care also is an indicator of the overall quality of healthcare system. Most healthcare providers create patient records during the first visit and also provide them with needed support for HIV care, such as case management, financial support, and medical assistance.[50] The quality of the linkage to care for PLWHA is related to the

individuals' utilization of HIV care services. For example, some structural-level barriers could impede timely linkage to care.[51] These barriers include health care system factors such as a lack patient navigation assistance and long appointment wait times, as well as social factors such as HIV stigma.[51] These factors also have been identified as barriers to HIV healthcare services.[39,52] Furthermore, interventions to improve linkage to care and HIV care utilization have used similar strategies, including health education, motivational counseling, and appointment assistance (e.g. peer accompany) and coordination.[53]

HIV care has shifted to a chronic disease care model because PLWHA are living longer and are more likely to develop chronic diseases related to the HIV virus, HIV inflammation, and treatment.[60] Therefore, service utilization becomes an essential component of HIV care for PLWHA if they are to receive the greatest benefit from their HIV treatment. However, previous studies have focused on HIV-specific care rather than on more general healthcare services among PLWHA. For example, previous studies have established associations between HIV care and HIV treatment outcomes, such as ART adherence, viral suppression, and mortality.[99-101] Very few studies have investigated service utilization in addition to HIV care.

Previous studies also have investigated individual healthcare services that are associated with linkage to care, such as care facility navigation and case management.[51,83,102] One study included multiple types of service needs and found an association between service needs and medication adherence, which is one HIV treatment outcome.[75] Previous studies have identified factors associated with linkage to care and service utilization;[39,52] however, no studies have reported a direct association between linkage to care and service utilization. Moreover, previous studies that investigated

service utilization did not distinguish between medical and support services,[75] which are two difference components in HIV care that might influence linkage to care differently. In this study, a wide range of healthcare services, medical services, and support services were included.

Specifically, the hypotheses of the study are that: 1) medical and support service utilization will be positively associated with linkage to care; and 2) unmet medical and support service needs will be negatively associated with linkage to care. The results of the study could support efforts to leverage programming aimed to simultaneously improve linkage to care and service utilization. The results could also be used to inform interventions designed to deliver needed services and to allocate health services to maximize the benefits of HIV care.

Methods

Participants

Participants (N =177) were involved in a Nevada health service needs assessment project. The purpose of the project was to identify HIV prevention and care service needs with the goal of developing and implementing an Integrated HIV Prevention and Care Plan. The project was conducted between January and March 2016.

PLWHA were recruited from a variety of provider locations and community organizations through flyers, social media, and word of mouth during the study period. A letter was sent to HIV clinics, community organizations and the Department of Health and Human Services in Nevada to request assistance with recruiting participants for the survey. The letter also included a website link for participants to complete the online

version of the survey. The inclusion criteria were being aged 18 years and older and currently living with HIV/AIDS. The sample included newly diagnosed patients, patients who were retained in HIV care for a period of time, and Ryan White clients receiving HIV care. In addition, the analyses were limited to participants who answered the linkage to care question: "After you were diagnosed with HIV, how long did it take before you first saw a doctor?" Respondents who did not answer this question (n=2) or who could not remember the length of time before being linked to care (n=10) were excluded from the study. The final analyses included 165 participants.

The survey was anonymous and took an average of 20 minutes to complete. Participants completed the self-administered questionnaire on paper in HIV clinics or online. The survey included questions that assessed sociodemographic factors, HIV disease status, service utilization, reasons for not getting services, linkage to care, reasons for late linkage to care, and medication adherence. All surveys and recruitment flyers were provided in English and Spanish. Participants received $10 gift cards for their participation.

Measures

The outcome variable was linkage to care, which was measured by the participants' response to the question: "After you were diagnosed with HIV, how long did it take before you first saw a doctor?" The survey provided seven options, which were "I got into care immediately", "less than a month", "1-3 months", "4-6 months", "more than 6 months", "I have not seen a doctor since my diagnosis", and "do not remember". with time frames. The variable was categorized into two levels based on the Centers for

Disease Control and Prevention (CDC)'s criterion: timely linkage to care (participants were linked to care less than one month after receiving an HIV diagnosis) and late linkage to care (participants were linked to care more than one month after receiving an HIV diagnosis).[17]

The independent variables were service utilization and unmet service needs. The service utilization question asked participants to indicate all of the services they were using or have used in the current year. The unmet service needs question asked participants to indicate all services that they needed but did not get. For both questions, participants chose from twenty-four services that were categorized into ten medical services and fourteen support services. Examples of medical services were medical care, specialty doctors, and dental care. Examples of support services were transportation, help filling out forms, and child care. Service utilization and unmet service needs were coded as continuous variables.

The most-cited reasons for late linkage to care were reported. The survey included a list of twelve reasons for "What problems did you have getting into a doctor's office after your diagnosis?" The reasons were categorized into two groups: service reasons and other reasons. An example of the service reason was "The wait time was too long." An example of an other reason was "I did not know where to go." Participants could select multiple reasons from the list.

Sociodemographic variables included age, gender, sexual orientation, and race/ethnicity. The number of years that a participant was HIV positive was also assessed.

Statistical analyses

Chi-square tests, two-sample *t*-tests, and Fisher's exact tests were conducted to assess possible between-group differences (timely- or late-linkage to care) regarding sociodemographic characteristics, number of years of HIV infection, overall services utilization, overall unmet service needs, and individual service utilization and unmet service needs. Chi-square tests and Fisher's exact tests were conducted for the categorical variables and two-sample *t*-tests were conducted for the continuous variables. Multivariable logistic regression models were also conducted to assess associations between service utilization, unmet service needs, and linkage to care.

Previous studies reported differences in linkage to care among different sociodemographic groups.[83] Therefore, in order to eliminate the influence of sociodemographic characteristics, age, gender, and race/ethnicity were controlled in the model. The number of years of HIV infection was also controlled because research has shown that it has an indirect association with participants' service needs.[82] Additionally, the most-cited problems that participants encountered during linkage to care stage were also reported. Analyses were performed using SAS 9.4 (Cary, NC).

Results

Sample characteristics

Approximately three-fourths (75.8%) of the participants reported they were linked to care less than one month after receiving an HIV diagnosis (Table 1). There were no significant differences between participants who reported timely and late linkage to care with respect to age, gender, sexual orientation, race/ethnicity, and number of years of

HIV infection. Timely and late linkage to care groups were not significantly different with respect to the number of medical (p=0.27) and support services (p=0.45) they utilized in the past year. The groups were also not significantly different regarding their unmet medical service needs (p=0.21) and unmet support service needs (p=0.73). However, the late linkage to care group reported needing more help obtaining health insurance compared to the timely linkage to care group (p=0.03). Additionally, the late linkage to care group reported a significantly greater need for a support group (p=0.048).

Table 1. Participant (N = 165) characteristics by linkage to care status.

Characteristics	Timely linkage to care, <1 month (125, 75.8 %)	Late linkage to care, >1 month (40, 24.2 %)	P-value
Age- continuous (mean, SD, years)	45 (12)	44 (13)	0.45[§]
Gender			0.26*
Male	87 (73.7)	33 (82.5)	
Female	31 (26.3)	7 (17.5)	
Sexual orientation			0.44*
Heterosexual	36 (28.8)	11 (27.5)	
Homosexual	63 (50.4)	24 (60.0)	
Other	26 (20.8)	5 (12.5)	
Race/ethnicity			0.05[#]
White, not Hispanic	39 (31.5)	15 (38.5)	
Black, not Hispanic	38 (30.6)	7 (18.0)	
Hispanic	21 (16.9)	13 (33.3)	
Other/unknown	26 (21.0)	4 (10.3)	
Number of years HIV infected - continuous (mean, SD, years)	12 (11)	14 (11)	0.47[§]
Used services this year			
Medical services (mean, SD, range 0-10)	2.4 (2.0)	2.8 (1.7)	0.27[§]
Support services (mean, SD, range 0-14)	2.6 (2.2)	2.9 (2.5)	0.45[§]
Unmet service needs			
Medical services (mean, SD, range 0-10)	1.2 (1.8)	0.9 (1.1)	0.21[§]
Support services (mean, SD, range 0-14)	0.7 (1.3)	0.8 (1.3)	0.73[§]
Individual used services and unmet service needs			
Help getting insurance			**0.03***
No	105 (85.4)	28 (70.0)	
Yes	18 (14.6)	12 (30.0)	

Need support groups			**0.048***
No	118 (95.9)	34 (87.2)	
Yes	5 (4.1%)	5 (12.8)	

SD= standard deviation
*Results from Chi-square test
[#] Results from Fisher exact test
[§] Results from Two-sample t-test

Service utilization and unmet service needs

In general, medical service utilization (Means = 2.4 and 2.8), support service utilization (Means = 2.6 and 2.9), unmet medical service needs (Means = 1.2 and 0.9), and unmet support service needs (Means = 0.7 and 0.8) were not high for the timely and late linkage to care groups (Table 1). As shown in Table 2, the analyses indicated that participants' service utilization and unmet services needs were not significantly associated with timely linkage to care (p>0.05).

Table 2. Associations between used services, unmet service needs, and linkage to care.

Services	Timely linkage to care		
	OR (95% CI)	AOR* (95% CI)	P-value
Used services			
Medical services	1.11 (0.92-1.33)	1.11 (0.89-1.38)	0.37
Support services	1.06 (0.91-1.24)	1.11 (0.93-1.32)	0.27
Unmet service needs			
Medical services	0.89 (0.69-1.14)	0.74 (0.52-1.04)	0.08
Support services	1.05 (0.80-1.39)	0.84 (0.56-1.25)	0.39

OR= odds ratio
AOR= adjusted odds ratio
*Adjusted for age, gender, race/ethnicity, and number of years HIV infected

A majority (72.0%) of the participants reported that they had no problems linking to care (Table 3). The most-cited service reasons for late linkage to care were a long wait time and appointment-related issues. The most-cited other reasons for late linkage to care were a desire to avoid thinking about their HIV diagnosis, lack of information about where to go for care, and fear of disclosure of HIV status.

Table 3. Participant reasons for late linkage to care.

What problems did you have getting into a doctor's office after your diagnosis?	Frequency (%)
I did not have any problem.	118 (72.0)
Service reason	
1. The wait time is too long.	7 (4.3)
2. I did not get a way to get to the appointment.	4 (2.5)
3. I could not get an appointment.	3 (1.9)
Other reason	
1. I did not want to think about having HIV.	17 (10.5)
2. I did not know where to go.	15 (9.2)
3. I did not want anyone to know I have HIV.	13 (8.0)

Discussion

The purpose of this study was to investigate associations among PLWHA's service utilization, unmet service needs, and HIV treatment outcomes, as represented by linkage to care. The results showed that the participants' linkage to care was not significantly associated with service utilization and unmet service needs.

The results do not support the hypotheses that service utilization and unmet service needs would be associated with linkage to care. There are several explanations for this result. First, a standardized measure of service utilization and unmet service needs is not yet available in the research literature. Previous studies used individual services such as patient navigation assistance and case management.[51,83,102] This study included a wide range of services in HIV care that were categorized into medical and support services. Research in this field would benefit if there were a universally accepted definition of services and a standardized measure of service utilization.

Second, commonly used HIV indicators include ART adherence, linkage to care, and viral suppression. Service utilization is not a commonly assessed indicator of HIV care and it typically is not a program objective.[17] Service utilization is not included in national HIV/AIDS strategies that guide program priorities and actions.[16] The absence of service utilization as an HIV indicator or as a focus of national HIV/AIDS strategies impedes funding for research and program efforts to further investigate and improve service utilization in an HIV care context.

In contrast, linkage to care, as a proxy indicator of HIV care,[17] is a focus of national goals and it has a standardized measure recommended by the CDC.[15] Programs and interventions with the aim of achieving the national goals of linkage to care have generated positive results.[103,104] Timely linkage to care rates for PLWHA increased from an estimated 59% to 66% from 2009 to 2011 to 78% in 2017,[4,14,105,106] which is similar to the 76% rate found in this study. The comparably slow progress in recent years regarding measurement and goals of service utilization may be one reason for the nonsignificant association between service utilization and linkage to care.

Third, service utilization covers all services in addition to HIV care in a health care context. Interventions with the goal of facilitating service utilization commonly focus on specific services.[107,108] These efforts often face challenges. For example, integrating mental health with HIV primary care may need multidisciplinary collaboration, administrative integration, and changes in referral procedures.[109] Although some interventions showed effectiveness,[110] unmet needs for ancillary services were still high.[72,73] As a result, although linkage to care and service utilization share some common structural-level factors, such as clinic (e.g., care facility navigation and appointment waiting time) and provider factors (e.g., HIV stigma),[39,51,52] improvement in service utilization requires a sustained effort and long-term interventions.

Fourth, PLWHA's service needs and service utilization might be influenced not only by structural-level factors, but also by individual-level factors, such as age, duration of HIV infection, and comorbidities.[82,111] Although some individual factors were controlled in the current study, it is possible that other potential factors (e.g. comorbidities, disease progress) influenced any possible significant association between service utilization and linkage to care.

The results indicated that participants who reported late linkage to care needed more help obtaining health insurance compared to individuals who reported timely linkage to care. Also, participants who reported late linkage to care showed a higher need for support groups. Late linkage to care can result in adverse health outcomes, such as prolonged viral suppression,[112] and reduced quality of life,[113] which in turn have a negative impact on the individuals' ability to work and their income. Therefore, it is not

surprising that participants who were linked to care late needed more assistance obtaining insurance as well as more emotional support.

Participants also reported factors other than service reasons for their late linkage to care. Previous studies found that many participants experienced psychological distress, depression, and anxiety at the time they received an HIV diagnosis.[114-116] This study's results are consistent with previous research that found that newly diagnosed individuals experienced HIV disclosure anxiety[117] and that they moved through a psychological process that progressed from denial to acceptance.[118] The results suggest that interventions that provide emotional support to newly diagnosed individuals also could help link them to care more quickly. Also, programs that provide information and resources (e.g. psychological assistance and counseling service), and that facilitate making appointments with HIV clinics, can help facilitate timely linkage to care.

The study had limitations. The cross-sectional study design limits inference of casual relationships among the variables. Furthermore, the self-report survey methods might be susceptible to recall and social desirability bias, perhaps leading to underreporting of late linkage to care. Nonresponse bias could occur if participants who responded to the survey were different from those who did not respond to the survey. However, although the study population was a convenience sample of PLWHA living in Nevada, the study sample is representative of the state's population.[119] The sample's distributions of age, gender, race/ethnicity, county of residence, and sexual orientation are consistent with Nevada's population.[119] Finally, the relatively small sample, particularly in the late linkage to care group, may have limited the study's statistical power to detect possible significant associations.

In conclusion, this study investigated relationships between a wide range of service utilization and individual services and linkage to care, which is one major indicator of HIV care continuum. More efforts are needed to develop appropriate measures to quantify service utilization. Service utilization goals need to be added to HIV care objectives in order to gain more attention and funding for research.

Chapter 4 Healthcare Utilization, Unmet Service Needs, and

HIV Treatment Outcomes among Racial/Ethnic Groups

Introduction

HIV disproportionately affects some racial/ethnic groups in the United States. African Americans have the highest proportion of individuals living with HIV/AIDS as well as the highest number of annual new diagnosed HIV cases. African Americans account for an estimated 41.7% of the 1.1 million people living with HIV/AIDS (PLWHA) despite representing only approximately 13% of the U.S. population.[54] From 2010 to 2017 U.S. HIV diagnoses for African Americans decreased 15%; however, of 37,832 new HIV diagnoses in 2018, 42% were African Americans.[55] Hispanics are also disproportionately affected by HIV. Although the Hispanic population makes up only 18% of the U.S. population it accounted for 22% of all PLWHA and 27% of newly diagnosed HIV cases in 2016.[54,56]

The Centers for Disease Control and Prevention (CDC) has a benchmark for timely linkage to care, which is within one month of receiving an HIV diagnosis.[15] African Americans have the lowest proportion of timely linkage to care among all race/ethnicity groups,[105] and they have a higher likelihood of non-initiation of care than Caucasians.[120] In addition, African Americans are less likely to receive antiretroviral therapy (ART) and retain in HIV care.[121-123] Hispanics have a lower rate of linkage to care after receiving an HIV diagnosis compared to non-Hispanic Caucasians.[105] Fewer proportions of Hispanics received HIV medical care and achieved viral suppression compared to non-Hispanic Caucasians.[105] African Americans, Hispanics, and other

minorities are more likely than Caucasians to participate in HIV screening tests at a later stage of HIV progression.[124]

As a result of these differences in linkage to care, ART adherence, and HIV care, there are also HIV treatment outcome differences among racial/ethnic groups. A lower proportion of African Americans has sustained viral suppression (54.0%), followed by Hispanics (60.0%), and Caucasians (66.6%).[105] African Americans also experience longer periods of high viral loads which increases the risk of transmission.[125] Among people who were receiving HIV care and who didn't sustain viral suppression, African Americans have longer durations of higher level viral loads (>1500 copies/mL) of 52.1%, followed by Hispanics (47.2%), and Caucasians (40.8%).[126]

The considerable variation in healthcare utilization by race/ethnicity may also have an impact on health disparities among racial groups. HIV-related stigma, inadequate access to culturally competent services, deficiency of services, and limited services are common structural-level barriers to HIV care access for racial/ethnic minorities.[76] For example, African Americans are more likely to live in areas that lack healthcare services or that have poorer quality healthcare.[77] Language can also act as a barrier to access to healthcare among people who do not speak English.[78] Racial/ethnic minorities are also more likely to be uninsured or underinsured.[79] In addition, race-based discrimination is associated not only with negative mental health, HIV health outcomes, and HIV care satisfaction,[80] it is also associated with a lower likelihood of service utilization.[81]

Research focusing on race/ethnicity disparities and service utilization in HIV medical care and treatment is limited. One study reported that approximately one-fourth of Hispanics had an unmet need for non-HIV medical services, such as dental and vision

care.[72] The unmet needs for support services, such as care management, and food or nutrition were also high among Hispanics.[73] Advances in HIV treatment have extended the life expectancies of PLWHA and therefore ancillary care and support services become essential components of HIV care when PLWHA live longer and chronic diseases become more prevalent.[60,61]

Little is known about possible racial/ethnic differences by various types of service utilization and HIV treatment outcomes, such as linkage to care and medication adherence. This study investigated service utilization differences in a wide range of medical and support services and differences in HIV linkage to care and medication adherence among racial/ethnic groups. The results of the study could contribute to an understanding of the impact of resource distribution in a racially/ethnically diverse population and inform programs that meet racial/ethnic groups' service needs to reduce HIV disparities.

Methods

Participants

Participants (N=177) were PLWHA who were involved in a statewide health service needs assessment project. The project collected survey data from PLWHA between January and March 2016 for the purpose of identifying HIV prevention and care service needs in Nevada. The goal of the project was to develop and implement an Integrated HIV Prevention and Care Plan.

PLWHA were recruited from a variety of HIV clinics and community organizations through flyers, social media, and word of mouth. Research staff sent a letter

to organizations, including HIV clinics, community organizations, and the Department of Health and Human Services in Nevada, to request assistance with recruiting participants for the survey. The letter also included a website link for participants to complete an online version of the survey. The inclusion criteria were participants aged 18 and older who were currently living with HIV/AIDS. The sample included newly diagnosed patients, patients who were retained in HIV care for a period of time, and Ryan White clients receiving HIV care. Two participants were excluded because they did not report their race/ethnicity. A total of 175 participants were included in the final analyses.

Participants completed a self-administered questionnaire on paper in the HIV clinics where they received the information about the survey or they completed the survey online. The survey took approximate 20 minutes to complete and included questions assessing sociodemographic factors, HIV disease status, service utilization, reasons for not getting services, linkage to care, and medication adherence. No personal identifying information was included in the survey. All surveys and recruitment flyers were provided in both English and Spanish. Participants received $10 gift cards for their participation.

Measures

The independent variable was the participants' self-reported race/ethnicity. The survey provided seven possible responses for this question which were coded into four groups: black or African American, Hispanic or Latino/a, white or Caucasian and other. The "other" group included American Indian or Alaskan Native, Native Hawaiian or Pacific Islander, Asian multi-racial participants.

The dependent variables were medical and support services utilization, ART adherence, and linkage to care. The service utilization question asked participants to check all the services they were using or have used in the current year. Participants chose from twenty-four services listed in the survey, such as mental health care, dental care, help getting food, and case management (Appendix A and B). The unmet service needs question asked participants to check all the services they needed but did not get. For both questions, participants chose from twenty-four services that were categorized into ten medical services and fourteen support services.

The number of checked utilized or unmet services were summed to create a variable ranging from 0 to 10 (medical) or 0 to 14 (support). Medical services and support services were analyzed as continuous variables. In addition, individual services that showed significant differences in utilization between racial/ethnic groups were also reported. Problems getting into the doctor's office after receiving an HIV diagnosis was assessed by the question: "I did not have any problems getting into a doctor's office after diagnosis." Whether the participants have received all needed services was assessed by the question: "I get all the services I need." Both questions had a "yes" or "no" response.

Medication adherence was measured by the participants' response to the question: "Have you ever stopped taking your HIV medicines in the last two years?" The survey provided three options to the question: "yes", "no" and "I do not take HIV medicines."

Linkage to care was measured by the participants' answer to the question: "After you were diagnosed with HIV, how long did it take before you first saw a doctor?" The survey provided seven options with time frames. The variable was coded into two levels based on the CDC's criterion: less than one month, and more than one month.[15]

Possible racial/ethnic differences regarding age, gender, and sexual orientation of the sample were also reported. These demographic variables are commonly used by the CDC to describe HIV distribution in the population.[127] The number of years a participant was HIV infected, which has been found to be associated with comorbidity, and which in turn, may be related to service needs, was also reported.[82]

Statistical analyses

The sample was stratified into the four race/ethnicity groups. One-way ANOVA, Chi-square tests and Fisher's exact tests were conducted to assess possible between-group differences (race/ethnicity) regarding sociodemographic factors and years of HIV infections. Multiple logistic regression models were conducted to assess possible between-group differences regarding HIV treatment outcomes. Multiple linear regression was conducted to assess possible between-group differences regarding utilized services and unmet service needs. For individual utilized and unmet service needs, multiple logistic regression was conducted to assess possible between-group differences. Only the individual services of the twenty-four services that showed significant between-group differences were reported. Sexual orientation was controlled in the models because there were significant differences among the four race/ethnicity groups. Number of years of HIV infected was controlled in the models because research has suggested an indirect association with participants' service needs.[82] Finally, the proportion of PLWHA who had no issues with linkage to care by race/ethnicity and the proportion of PLWHA who have received all needed services were also reported. Between-group differences were

assessed using multiple logistic regression and controlling for sexual orientation and number of years of HIV infected. SAS 9.4 (Cary, NC) was used to conduct all analyses.

Results

Sample characteristics

The race/ethnicity of the sample ranged from 19% other race/ethnicity to 32% Caucasian (Table 1). The other race/ethnicity group (n=33) included 2 American Indian or Alaska Natives, 5 Native Hawaiian or Pacific Islanders, and 6 Asians, as well as 20 participants of "other" race/ethnicities. There were no significant between-group differences (p>0.05) regarding age, gender, or number of years HIV infected. There were significant between-group differences regarding sexual orientation status (p=0.03). The Hispanic and Caucasian groups indicated high proportions of homosexuality whereas the other race/ethnicity group indicated the highest proportion of bisexuality.

Table 1. Participant (N=175) characteristics by race/ethnicity.

Characteristics	Caucasian n (%)[1]	African American n (%)[1]	Hispanic n (%)[1]	Other n (%)[1]	p-value
Frequency	56 (32)	49 (28)	37 (21)	33 (19)	
Mean Age (SD)	45 (12)	46 (11)	41 (11)	49 (12)	0.09[§]
Gender					0.08*
Male	43 (76.8)	30 (61.2)	30 (85.7)	20 (74.1)	
Female	13 (23.2)	19 (38.8)	5 (14.3)	7 (25.9)	
Sexual orientation					**0.03***
Heterosexual	19 (33.9)	19 (38.8)	6 (16.2)	8 (24.2)	
Homosexual	30 (53.6)	24 (49.0)	20 (54.1)	13 (39.4)	
Bisexual	7 (12.5)	6 (12.2)	11 (29.7)	12 (36.4)	
Mean number of years HIV infected (SD)	13 (10)	13 (10)	15 (12)	12 (11)	0.37[§]

Note.

a: SD= standard deviation

b: [1]Percentage unless otherwise indicated

c:*Results from Chi-square test

d: [§] Results from One-way ANOVA

e: [#] Results from Fisher's exact test

Service utilization and unmet service needs among racial/ethnic groups

As shown in Tables 2 and 3, there were no significant between-group differences

(p>0.05) regarding service utilization, unmet service needs, linkage to care, or medication

adherence.

Table 2. Medical and support service utilization, unmet service needs, linkage to care, and medication adherence by race/ethnicity.

Healthcare services and HIV treatment outcomes	Caucasian	African American	Hispanic	Other
Used services this year				
Mean medical services (SD) range = 0-10	2.7 (1.9)	2.7 (2.2)	2.1 (1.6)	2.3 (1.8)
Mean support services (SD) range = 0-14	2.7 (2.3)	2.9 (2.4)	2.5 (2.2)	2.3 (2.0)
Unmet service needs				
Mean medical services (SD) range = 0-10	1.4 (1.5)	1.1 (1.7)	1.1 (1.9)	0.8 (1.4)
Mean support services (SD) range = 0-14	0.6 (0.9)	0.8 (1.3)	0.8 (1.3)	0.8 (1.5)
Linkage to care, n (%)				
More than 1 month	15 (27.8)	7 (15.6)	13 (38.2)	4 (13.3)
Less than 1 month	39 (72.2)	38 (84.4)	21 (61.8)	26 (86.7)
Medication adherence, n (%)				
No	20 (36.4)	13 (30.2)	12 (34.3)	4 (14.8)
Yes	35 (63.6)	30 (70.0)	23 (65.7)	23 (85.2)

Note.
a: SD= standard deviation

Table 3. Between-group (race/ethnicity) differences regarding medical and support service utilization, unmet service needs, linkage to care, and medication adherence.

Healthcare services and HIV treatment outcomes		Caucasian	African American	Hispanic	Other
Utilized medical services	Coefficient (SE)	Ref	-0.04 (0.40)	-0.67 (0.45)	-0.12 (0.49)
	p-value*		0.92	0.13	0.81
Utilized support services	Coefficient (SE)	Ref	0.22 (0.45)	-0.32 (0.51)	-0.28 (0.56)
	p-value*		0.63	0.53	0.62
Unmet medical services	Coefficient (SE)	Ref	-0.32 (0.35)	-0.22 (0.39)	-0.62 (0.43)
	p-value*		0.36	0.58	0.15
Unmet support services	Coefficient (SE)	Ref	0.13 (0.24)	0.22 (0.27)	0.08 (0.30)
	p-value*		0.60	0.42	0.79
Late linkage to care	AOR (95% CI)	Ref	2.62 (0.85-8.07)	0.53 (0.20-1.42)	3.48 (0.71-17.08)
	p-value#		0.09	0.21	0.13
Medication non-adherence	AOR (95% CI)	Ref	0.74 (0.30-1.79)	0.95 (0.36-2.50)	0.28 (0.07-1.08)
	p-value#		0.50	0.92	0.06

Note.

a: SE= standard error

b: AOR=adjusted odds ratio

c: CI= confident interval

c: *Results from multiple linear regression

d: #Results from multiple logistic regression

e: All analyses adjusted for sexual orientation and number of years of HIV infected

Table 4. Between-group (race/ethnicity) differences regarding individual services.

Individual services	Caucasian	African American	Hispanic	Other
Adjusted Odds Ratio* (95% CIs)				
Utilized medical care	Ref	**0.33** (0.13-0.84)	0.54 (0.18-1.63)	0.71 (0.21-2.45)
Utilized mental health care	Ref	0.73 (0.31-1.75)	**0.16** (0.04-0.62)	0.35 (0.10-1.22)
Utilized help understanding medicines	Ref	2.77 (0.97-7.89)	1.70 (0.52-5.56)	**5.58** (1.69-18.42)
Utilized help filling out forms	Ref	0.38 (0.04-3.86)	**5.11** (1.11-23.5)	-
Utilized case management	Ref	0.78 (0.31-1.94)	**0.23** (0.06-0.88)	1.03 (0.34-3.09)
Utilized HIV and health classes	Ref	1.02 (0.40-2.61)	**0.24** (0.06-0.96)	0.61 (0.17-2.19)
Utilized financial help	Ref	0.44 (0.14-1.42)	**0.19** (0.04-0.97)	0.82 (0.22-3.01)

Note.

a: CI= confident interval

b: *Results from multiple logistic regression adjusted for sexual orientation and number of years HIV infected.

There were significant between-group differences for seven (of twenty-four) individual utilized services (Table 4). The African American group was 3 times less likely to have utilized medical care service than the Caucasian group (AOR=0.33). The Hispanic group was 6 times less likely to have utilized mental health service than the Caucasian group (AOR=0.16). Compared to the Caucasian group, the Hispanic group reported lower service utilization in individual support services, including case management (AOR=0.23), HIV and health classes (AOR=0.24), and financial help

(AOR=0.19). Furthermore, the other race/ethnicity group was greater than 5 times more

likely to have utilized help to understand medicines service than the Caucasian group

(AOR=5.58). The Hispanic group was 5 times more likely to have utilized help filling out

forms service than the Caucasian group (AOR=5.11).

Table 5. Results of analyses reporting problems getting into the doctor's office after
diagnosis and receiving needed services by race/ethnicity.

	Total n (%)	Caucasian n (%)	African American n (%)	Hispanic n (%)	Other n (%)
I did not have any problems getting into a doctor's office after the diagnosis.					
No	54 (31.0)	20 (36.4)	9 (18.4)	10 (27.0)	15 (45.5)
Yes	120 (69.0)	35 (63.6)	40 (81.6)	27 (73.0)	18 (54.6)
AOR* (95% CI)		Ref	**2.60** (1.00-6.75)	1.85 (0.66-5.16)	0.83 (0.30-2.30)
I get all the services I need.					
No	160 (92.5)	51 (94.4)	45 (91.8)	34 (91.9)	30 (90.9)
Yes	13 (7.5)	3 (5.6)	4 (8.2)	3 (8.1)	3 (9.1)
AOR* (95% CI)		Ref	1.18 (0.22-6.31)	0.87 (0.13-5.76)	1.76 (0.26-11.72)

Note.
a: AOR= adjusted odds ratio
b: CI= confident interval
c: *Results from multiple logistic regression adjusted for sexual orientation and
number of years HIV infected

Finally, as shown in Table 5 the African American group was 2.6 times more

likely to have problem-free linkage to care than the Caucasian group (AOR=2.60). A

majority of the participants (92.5%) reported that they did not get all services they needed; however, no significant racial/ethnic differences were found.

Discussion

The purpose of this study was to investigate racial/ethnic differences regarding service utilization, linkage to care, and medication adherence among PLWHA. Although previous studies reported that racial/ethnic minorities have adverse results at various stages of the HIV care continuum that may due to delayed or lack of access to healthcare services,[105,120-126] this study did not find significant racial/ethnic groups differences regarding overall service utilization and unmet service needs.

The lack of significant between-group differences regarding service utilization and unmet service needs by race/ethnicity could be explained by the following reasons. Previous studies reported that stigma is one barrier to HIV testing and care.[39,129-130] National anti-stigma campaigns may have possibly reduced the effects of stigma on HIV care.[131,132] For example, recent studies showed that African Americans are more likely to be offered HIV testing by healthcare providers than Caucasians who have similar rates of HIV risk behaviors.[133] In addition, African American college students are more likely to request testing for HIV and they have more positive testing attitudes compared to Caucasian college students.[134] The results of this study support this notion. The African American participants had the highest percentage of timely linkage to care (84.4%); a percentage that is very close to the CDC goal of 85%.[135]

Although the study did not find significant between-group differences regarding linkage to care, Caucasian participants were 2.6 times more likely to have problems with

linkage to care compared to the African Americans participants. The previously referenced anti-stigma campaigns, that focus primarily on reducing HIV stigma for African Americans, may have had a substantial effect on healthcare providers who now may be more likely to provide referrals to facilitate linkage to care when they have African American patients who tested HIV positive.

The study did not find significant between-group differences regarding medication adherence. Medication adherence is influenced by many factors such as age, gender, socioeconomic status, individual behaviors, and chronic conditions.[136-138] The possible influence of race/ethnicity on medication adherence could be too subtle to detect in this study.

The African American participants were 3 times less likely to have utilized medical care service than the Caucasian participants. Previous studies found that high service utilization levels are associated with improved health outcomes.[139] More efforts should be taken to improve medical care access for African Americans.

The Hispanic participants were 6 times less likely to have utilized mental care service than the Caucasian participants. This result could be explained by the stigma toward mental health illness that exists among Hispanics. Research has shown that Hispanics have higher level of mental illness stigma and were less likely to seek health care for mental illness.[140,141] Future interventions that aim to improve mental health service utilization among PLWHA could target Hispanics with the specific goal of reducing mental health stigma. The Hispanic participants were less likely to have utilized three support services, including financial help, case management, and HIV and health

classes than the Caucasian participants. Future programs should focus on improving certain ethnic group's service needs in HIV care.

The Hispanic participants were 5 times more likely to have utilized help filling out forms compared to the Caucasian participants and the other race/ethnicity participants were greater than 5 times more likely to have utilized help to understand medicines compared to the Caucasian participants. These two services are related to health literacy and language. Language could be a barrier for Hispanics and individuals in the other race/ethnicity group when completing forms or understanding medicines if only English forms and instructions are available. Although the practice is becoming more common, the results suggest that having forms and instructions available in Spanish as well as English would facilitate Hispanics' utilization of healthcare. Bilingual services for non-English-speaking clients would also be helpful.

Previous studies showed that American Indians and Alaska Natives have a high prevalence of depression, poverty, and HIV-related stigma; however, they are less likely to receive needed services, such as mental health care and peer support services.[142,143] Previous studies also reported that barriers, such as language, health literacy, and access to insurance make it more difficult for Asians to utilize healthcare service.[144] Particular attention must be payed to this race/ethnicity group, which included American Indians/Alaskan Natives, Native Hawaiians/Pacific Islanders, Asian, and multi-racial participants, to provide more resources and support, and to remove barriers to healthcare services.

The study had limitations. Causal associations cannot be inferred because of the cross-sectional study design. Self-reported data are susceptible to social desirability bias

and recall bias, thus perhaps leading to underreporting of late linkage to care or inaccurate reporting of service utilization. The study did not include other possible contributing factors, such as social-economic status, which might be associated with race/ethnicity or service utilization. Also, the study used a convenience sample of PLWHA who received HIV care in Nevada and therefore the sample might not be representative of the national PLWHA population. Finally, the sample included only participants who were linked to care and therefore the results of the study are not representative of all PLWHA.

Implications for Health Behavior or Policy

The results showed that 92.5% participants did not receive all the services they needed. Alleviating service needs is now an essential component of HIV care. Reducing HIV health disparities and inequities and increasing access to care and improving health outcomes among PLWHA are two of three main federal goals of the National HIV/AIDS Strategy[16] and they are priorities of the CDC as well.[55] The results suggest that increasing funding to meet PLWHA's service needs is necessary if these goals are to be met.

Federal funding for HIV/AIDS increased from $8 million in fiscal year (FY) 1982 to $34.8 billion in FY 2019.[145] Mandatory funding, which is the funding source for programs such as Medicaid and Medicare, is determined by eligibility requirements and care costs for people who are eligible for the programs.[145] In contrast, discretionary funding is determined annually by Congress and it funds domestic programs (e.g., the Ryan White HIV/AIDS program), basic needs (e.g., housing), and research. The number

of PLWHA is increasing and therefore both types of funding need to be increased annually.

Some policy-level changes have been made to expand insurance coverage for PLWHA because of the implementation of the Patient Protection and Affordable Care (ACA).[33,146] Medicaid coverage for PLWHA significantly increased from 36% in 2012 to 42% in 2014.[147] The increase was due to Medicaid expansion.[147] On the other hand, states with non-Medicaid expansion decreased their Medicaid coverage from 31% in 2012 to 28% in 2014.[147] Medicaid expansion is still needed to increase insurance coverage, especially in states that have resisted Medicaid expansion. Furthermore, barriers such as insurance illiteracy and difficulties maintaining coverage and requalifying for insurance, must be reduced or removed to enable more PLWHA to access insurance.[148]

Programs and policy making must continue to focus on eliminating coverage gaps if more PLWHA are to access needed services. For example, the current Ryan White HIV/AIDS Program B has household income and insurance coverage requirements for PLWHA to be eligible for HIV medical and support services.[149] Changing the poverty thresholds and insurance requirements could result in more PLWHA receiving coverage.

Federal and regional programs must also allocate funding to address specific service needs for racial/ethnic groups. For example, Hispanics might need bilingual language services during clinical visits and to apply for insurance and other services. In addition, programs that aim to eliminate mental health stigma are particularly needed for Hispanic PLWHA, and African Americans may need more support to expand access to medical care and assistance paying for medications.

More efforts must be taken to quickly link individuals to care after they receive an HIV diagnosis, especially for Hispanics and Caucasians. Training of practitioners to immediately refer individuals who receive an HIV positive test to HIV specific care should be implemented in all primary care facilities. Relevant information with a list of resources should be available at primary care clinics. Primary care providers must pay attention to all individuals who receive an HIV positive test result regardless of their race/ethnicity and consistent anti-stigma efforts should be in place in healthcare facilities.

PLWHA rely on medications after they have started ART. Longer life expectancy is a major success of ART; however, it adds burden to the health care system and increases the costs of medications and care. ART medications account for 60% of the lifetime costs of HIV treatment and care.[150] The biggest buyer is the federal government, rather than individual customers, when insurance coverage is expanded. Monthly ART medication costs range from $2,000 to $5,000; and the lifetime treatment cost is more than half-a-million dollars.[151] Data show that the cost of ART medications in the U.S. market is much higher than some international markets.[152] The U.S. spends about $20 billion a year on ART medications.[152] The federal government could use its enormous purchasing power to negotiate better pricing and thus lower the cost of ART medications. Other strategies include implementing a bidding system to obtain the lowest price and launching funding initiatives to encourage the development of new drugs, generic drugs, and combined drugs that may lead to lower prices overall in the market.

Chapter 5 Dissertation Summary, Conclusions, and Recommendations

The aims of this study were to investigate associations between healthcare service utilization and unmet service needs with HIV treatment outcomes, as represented by linkage to care and ART adherence, and to assess possible racial/ethnic differences regarding service utilization, unmet service needs, and HIV treatment outcomes among PLWHA.

Summary of Results

The mean age of the sample was 45 and 73% were males. The participants had a mean of 13 years of HIV infection. The race/ethnicity of the sample was 32% Caucasian, 28% African American, 21% Hispanic and 19% other. Approximately two-thirds of the participants were linked to HIV care in one month or less. The study found that the participants generally had low service utilization rates and a large proportion of them did not receive all needed services.

Unmet service needs were negatively associated with ART adherence, however, utilizing service was not associated with ART adherence. The study did not find significant associations between service utilization and unmet service needs and linkage to care. Furthermore, participants who reported late linkage to care showed a significantly higher need for help obtaining insurance service and a higher need for support groups.

No race/ethnicity group differences were found regarding service utilization, unmet service needs, linkage to care, and ART adherence. There were significant race/ethnicity differences regarding individual service utilization. The African American group was 3 times less likely to have utilized medical care service than the Caucasian

group. The Hispanic group was 6 times less likely to have utilized mental health service than the Caucasian group. Compared to the Caucasian group, the Hispanic group reported lower service utilization in individual support services, including case management, HIV and health classes, and financial help. Furthermore, the other race/ethnicity group was greater than 5 times more likely to have utilized help to understand medicines service than the Caucasian group. The Hispanic group was 5 times more likely to have utilized help filling out forms service than the Caucasian group. The African American group was 2.6 times more likely to have problem-free linkage to care than the Caucasian group.

The results of this study support the ABM in that service utilization was associated with health behaviors and health outcomes. Enabling factors (defined as support services in this study) and the healthcare environment (defined as medical services in this study) influence patient health outcomes.[37] The results of this study highlight that both support services and medical services are essential parts of HIV care. The results underscore the importance of addressing unmet service needs in addition to the resources available in the HIV care context.

Conclusions

The results indicated that the participants' unmet service needs were negatively associated with ART adherence, but they were not associated with linkage to care. Although service utilization and unmet needs were both generally low, a majority of the participants reported they did not receive all of the services they needed. The results are consistent with previous studies which reported that unmet service needs (e.g., food

insecurity and housing instability) were associated with HIV treatment outcomes, including poor ART adherence, unsuppressed viral load, and less access to care.[91-94]

Programs must make continuous efforts to improve service utilization and remove barriers to the access of needed services. These efforts will contribute to the improvement of HIV outcomes. However, perhaps other potential factors, such as the individuals' specific needs, health status, and comorbidity status, all of which might be associated with current service utilization, muted potential associations between utilized services and HIV treatment outcomes.

HIV disproportionately affects people living in poverty.[95] Further, because PLWHA are living longer and thus their comorbidities rates are also increasing, the need for comprehensive care is also increasing.[60] However, at the same time fulfilling basic needs are a prominent concern among PLWHA.[96] These factors create challenges to meeting the service needs of PLWHA. Although the Ryan White program provides medical and support services for a large number of PLWHA,[97] it is possible that service coverage gaps still exist. More funding must be provided to deliver free or low-cost services for PLWHA. Health care practice and health promotion programming for PLWHA can also be informed by examining the reasons that the participants cited for not obtaining services.

Reasons for not obtaining services included lack of insurance coverage and factors related to cost and eligibility. Health promotion programming should focus not only on introducing new services at the community level, but also work to optimize the availability and awareness of current services. In addition, health promotion and policy advocacy efforts can focus on expanding as well as explaining the intricacies of health

insurance coverage, reducing the individual financial burden, disseminating information about service resources, and filling gaps in support services such as improving navigation in HIV care facilities and facilitating transportation. Patient-centered services would be helpful if they became more oriented toward making services more accessible, feasible, and convenient. Previous research examining integrated HIV care indicated some strategies that could be used to address service needs of PLWHA. These strategies included enhancing collaboration and service integration, such as co-locating services, partnering to leverage resources, and staff cross-training.[98]

The results indicated that participants who reported late linkage to care needed more help obtaining health insurance compared to individuals who reported timely linkage to care. Also, participants who reported late linkage to care showed a higher need for support groups. Late linkage to care can result in adverse health outcomes, such as prolonged viral suppression[112] and reduced quality of life,[113] which in turn, have a negative impact on the individuals' ability to work and their income. Therefore, it is not surprising that participants who were linked to care late needed more assistance obtaining insurance as well as more emotional support.

Participants also reported factors other than service reasons for their late linkage to care. Previous studies found that many participants experienced psychological distress, depression and anxiety at the time they received an HIV diagnosis.[114-116] This study's results are consistent with previous research that found that newly diagnosed individuals experienced HIV disclosure anxiety[117] and that they moved through a psychological process that progressed from denial to acceptance.[118]

This study found that health disparities among racial/ethnic groups exist in certain services, such as medical care, mental health care, and case management. Caucasian participants were 2.6 times more likely to have problems with linkage to care compared to the African Americans participants. The previously referenced anti-stigma campaigns that focus primarily on reducing HIV stigma for African Americans may have had a strong effect on healthcare providers. Providers may now be more aware and provide referrals to facilitate linkage to care when they have African American clients who tested HIV positive. Efforts must be taken to improve linkage to care of all individuals who receive an HIV positive test result regardless of their race/ethnicity. Primary care providers need to work on solving individuals' problems when linking them to care (e.g. psychological distress or fear disclosure of HIV status).

The African American participants were less likely to have utilized medical care service compared to the Caucasian participants. Previous studies found that high service utilization levels are associated with improved health outcomes.[139] More efforts should be taken to improve medical care access for African Americans.

The Hispanic participants were less likely to have utilized mental care service compared to the Caucasian participants. This result may be explained by the stigma towards mental health illness that exists among Hispanics. Research has shown that Hispanics demonstrated higher level of mental illness stigma and were less likely to seek health care for mental illness.[143,144] Future interventions that aim to improve mental health service utilization among PLWHA could target Hispanics with the specific goal of reducing mental health stigma.

The Hispanic participants were more likely to have utilized help filling out forms compared to the Caucasian participants and the other race/ethnicity participants were more likely to have utilized help to understand medicines compared to the Caucasian participants. These two services are related to health literacy and language. Language could be a barrier for Hispanics and participants in the other race/ethnicity group when completing forms or understanding medicines if only English forms and instructions are available. Although the practice is becoming more common, the results suggest that having forms and instructions available in Spanish as well as English would facilitate Hispanics' utilization of healthcare. Bilingual services for non-English-speaking clients would also be helpful.

Previous studies showed that American Indians and Alaska Natives have a high prevalence of depression, poverty, and HIV-related stigma; however, they are less likely to receive needed services, such as mental health care and peer support services.[140,141] Previous studies also reported that barriers, such as language, health literacy, and access to insurance make it more difficult for Asians to utilize healthcare service.[142] Particular attention must be payed to this race/ethnicity group, which included American Indians/Alaskan Natives, Native Hawaiians/Pacific Islanders, Asian, and multi-racial participants, to provide more resources and support, and to remove barriers to healthcare services.

Federal and regional programs must allocate funding to address specific service needs and improve healthcare services for certain racial/ethnic groups. More efforts should be made to improve medical care access for African Americans. Hispanics and other non-English-speaking clients may need bilingual language services during clinical

visits and to apply for insurance and other services. In addition, programs that aim to eliminate mental health stigma are needed especially for Hispanic PLWHA.

More efforts must be taken to quickly link individuals to care after they receive an HIV diagnosis. The training of practitioners to promptly link individuals who receive an HIV positive test and refer them to care should be implemented in all primary care facilities. Relevant information with a list of resources (e.g., HIV clinics and HIV doctors) should be available at primary care clinics. Primary care providers must pay attention to all individuals who receive an HIV positive test result regardless of their race/ethnicity and consistent anti-stigma efforts should be in place in healthcare facilities.

Finally, Nevada has a high rate of new-diagnosed HIV cases with a rate of 20 new HIV infections per 100,000 population in 2017[10,12] compared to 14 new infections per 100,000 population at the national level.[11] In addition, 9.7% of Nevada's population lives in 14 rural and frontier counties. The geographic distribution of Nevada's population is one challenge to implementing programs and training to improve timely linkage to care, especially in the rural communities. Particular attention and efforts must be taken to eliminate barriers to linking newly diagnosed individuals to HIV care. For example, offering remote services or counseling would be an option to deliver needed services to PLWHA who reside in Nevada's rural communities. One national HIV prevention strategy that could be implemented more intensively in Nevada is Test-and-Treat, which aims to eliminate HIV through early detection, early diagnoses, and effective treatment of the population at risk.[16,153]

Strengths and Limitations

The study had some limitations. The cross-sectional study design limits inference of casual relationships among the variables. Future studies could utilize a longitudinal study design to assess prospective relationships between service utilization and HIV outcomes over time. The self-report survey methods might be susceptible to recall and social desirability bias, thus leading to underreporting of important study outcomes, such as late linkage to care. The measure of medication adherence was dichotomous, which determined only if participants had ever stopped taking medication. An instrument that more fully measures the quantity of adherence (e.g., how many doses a participant missed in a specified time period) could be used to assess levels of adherence. This measure would also permit a more in-depth comparison of the results to previous studies. However, this study included a wide range of services of HIV care rather than individual services. Finally, the study used a small convenience sample of PLWHA. The results of the study cannot be generalized to participants who were PLWHA but were not receiving HIV care, or who dropped out of HIV care.

Despite the limitations, to my knowledge, this is the first published study to utilize the ABM to explain the results in the HIV care context and investigate a wide range of service utilization and HIV treatment outcomes. One strength of the study is that it included both medical and support services, utilized services and unmet service needs, and almost all services in the HIV care context. Although the sample size was relatively small, significant associations such as unmet service needs and ART adherence were detected. The results have implications to improve HIV treatment outcomes by allocating funding and resources to improve specific and highly needed services.

Public Health Implications

The results of the study indicate that improving service utilization could contribute to HIV treatment outcomes. Future HIV care models, that facilitate ancillary services and integration of healthcare services with HIV care, are likely to show more positive health outcomes. In addition, public health programing should focus efforts on meeting certain racial/ethnic groups and individuals' unmet service needs. Programs that target specific race/ethnicity groups with the goal of providing certain services, such as medical care for African Americans and mental health care for Hispanics, would be more effective. In addition, an anti-stigma campaign that focuses on mental health might effectively improve mental health service utilization among Hispanics.

The service utilization rates of PLWHA are generally low and many of them have unmet service needs. At the same time, PLWHA face barriers related to access to healthcare services. Barriers might exist in multiple levels of the Social-Ecological Model,[154] such as the healthcare environment, clinics, and providers. Future programs should work on facilitating service utilization and removal of barriers. In addition, service utilization among PLWHA must be based on long-term planning and goal setting to increase the sustainability of available services. Interventions that aim to improve service utilization may face challenges, such as changes in current procedures or guidelines. Therefore, multidisciplinary collaborative efforts among healthcare providers, clinics, state agencies, and organizations (e.g., non-profit organizations that provide nutrition or transportation services) are needed to create new procedures and shorten waiting times for PLWHA to obtain needed services.

Rapid initiation of ART refers to starting ART within one week of HIV diagnosis, including same day treatment starts.[155] Research shows that rapid initiation of ART can lead to improved HIV outcomes, including linkage to care at 3 months, viral suppression at 12 months, and retention in care.[156-158] This study found various reasons for late linkage to care, such as appointment-related issues. Therefore, rapid initiation of ART can meet individuals' needs by providing clinical, medical, and medication services immediately after an HIV diagnosis. It is a promising strategy that will likely improve HIV outcomes.

Future Research

This study highlighted areas that need further research, particularly the need to create a comprehensive research agenda regarding service utilization by PLWHA. Future studies that use the ABM as a framework should consider including both utilized services and unmet service needs as components of healthcare services. Additionally, future research could include more ABM constructs such as clinic and provider factors, and explore their possible relationships with service utilization in HIV care.

Furthermore, research in the HIV healthcare utilization field does not have a standardized measurement of service utilization. The categorization of services of HIV care is also inconsistent.[72,74,75] Research in this field would benefit if there was a universally accepted definition of services and a standardized measure of service utilization.

Longitudinal studies must be conducted to investigate long-term consequences of service utilization on HIV treatment outcomes and to assess causal associations among

the important variables. Other possible research areas include creating large datasets by pooling data from multiple clinics and hospitals, such as data from electronic health records. This will result in a large sample size that increases the statistical power necessary to detect possible significant associations among variables.

The study revealed that unmet service needs are negatively associated with ART adherence. Future research should be conducted to understand the impact of service utilization and unmet service needs on other HIV treatment outcomes, such as viral suppression and mortality. Also, future studies could focus on elucidating the mechanisms by which the impact may occur, such as via the influence of specific comorbidities on variations in ART treatment outcomes.

Future research could assess associations, as posited by the ABM, between HIV healthcare utilization and HIV treatment outcomes using structural equation modeling (SEM). SEM allows a comprehensive testing of theory-based relationships and patterns (e.g., mediation) in one model.[159,160] For example, the potential mediating influence of comorbidities in the association between service utilization and unmet service needs and ART treatment outcomes could be explored using SEM.

Also, as previously discussed, some variables (e.g. HIV healthcare utilization, ART adherence) do not have standardized measures. SEM is a useful analytical approach to addressing this problem. Multiple measures of variables could be used to increase the validity of measures. For example, ART adherence data could be collected through self-report, doctor's prescription records, and pharmacy records. Unreliable measures of theory constructs could be removed to increase the validity of the construct.

The results did not support the hypotheses that service utilization and unmet service needs would be associated with linkage to care. Future research needs to be conducted with a larger sample size to increase the statistical power, as well as to understand factors that result in optimal service utilization and timely linkage to care. It is vital to continue investigating associations between service utilization and other HIV treatment outcomes, for example viral suppression, as well as to understand the pathways by which it may occur.

In conclusion, the study revealed important relationships between unmet service needs and HIV treatment outcomes, such as ART adherence and race/ethnicity differences in certain service utilization. The findings of this study therefore could be used to improve medical and support services to achieve better HIV-related health outcomes. The results could inform health promotion programs that aim to alleviate service needs among PLWHA. Federal and regional programs must allocate funding to address specific service needs and improve healthcare services for certain racial/ethnic groups.

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Appendices

Appendix A: Survey

If you are HIV positive, we need your help! Thank you for filling out this survey that will help improve HIV care and prevention in Nevada.

(The survey is also online https://www.surveymonkey.com/s/NVHIVclient15 or scan the QR code.)

1. **How old were you when you were diagnosed with HIV?**

    _____years (If you are not HIV positive, please stop taking the survey.)

2. **After you were diagnosed with HIV, how long did it take before you first saw a doctor? (Check one answer)**

    ☐ I got into care immediately
    ☐ Less than a month
    ☐ 1-3 months

    ☐ 4-6 months
    ☐ More than 6 months

    ☐ I have not seen a doctor since my diagnosis
    ☐ Don't remember

3. **What problems did you have getting into a doctor's office after your diagnosis? (Check all that apply)**

    ☐ I didn't have any problems
    ☐ I didn't know where to go
    ☐ The wait time was too long
    ☐ I couldn't get an appointment
    ☐ They didn't have a time that worked with my schedule
    ☐ I didn't have a way to get to the appointment
    ☐ I didn't want to see a doctor right away

    ☐ I didn't feel sick
    ☐ I didn't have child care
    ☐ I didn't want to go alone
    ☐ I didn't want to think about having HIV
    ☐ I was too nervous to see a doctor
    ☐ I didn't want anyone to know I have HIV
    ☐ Other (please specify:

4. **Please check all the services you are <u>using now</u> or have used this year:**

    ☐ Medical care
    ☐ Help paying for medicines
    ☐ Help understanding medicines and how to take them
    ☐ Help getting food
    ☐ Dental care
    ☐ Help getting health insurance
    ☐ Vision care
    ☐ Financial help

    ☐ Transportation
    ☐ Mental health care
    ☐ Help filling out forms
    ☐ Specialty doctors
    ☐ Therapy (occupational, speech, physical)
    ☐ Nutrition help
    ☐ Referrals to get other health care or services
    ☐ Interpretation or translation into my language
    ☐ Help getting off drugs or alcohol

5. What services do you <u>need</u> that you don't get? (Check all that apply)

☐ Medical care
☐ Help paying for medicines
☐ Help understanding medicines and how to take them
☐ Help getting food
☐ Dental care
☐ Help getting health insurance
☐ Vision care
☐ Financial help

☐ Transportation
☐ Mental health care
☐ Help filling out forms
☐ Specialty doctors
☐ Therapy (occupational, speech, physical)
☐ Nutrition help
☐ Referrals to get other health care or services
☐ Interpretation or translation into my language
☐ Help getting off drugs or alcohol

☐ Child care
☐ Case Management
☐ HIV and health classes
☐ Free condoms
☐ Home health care
☐ Legal help
☐ Support groups
☐ Other (please specify):

_____

6. Why don't you get them? (Check all that apply)

☐ I don't know where to go
☐ I can't get an appointment
☐ I don't have transportation
☐ I don't have child care
☐ Services cost too much
☐ Services not covered by insurance
☐ It takes too much time
☐ I don't qualify for the services
☐ Eligibility process is too hard

☐ I have other things on my mind
☐ Services not available
☐ Services not available near me
☐ Services not available in my language
☐ Providers did not respect me
☐ Long wait lists
☐ I didn't want anyone to know I was HIV positive
☐ Does not apply/I get all the services I need
☐ Other (please describe):

_____

7. Have you ever stopped taking your HIV medicines in the last two years?

☐ I don't take HIV meds
☐ No   ☐ Yes

8. If yes, why did you stop taking them? (check all that apply)

☐ Couldn't afford them
☐ They made me feel really bad
☐ Insurance stopped covering it
☐ Lost my insurance
☐ Changed my insurance
☐ I missed a doctor's visit
☐ I felt healthy

☐ I was on a break from taking HIV meds, directed by my doctor
☐ I was on a break from taking HIV meds, decided by myself
☐ Other (please describe): _____

9. What do you do to prevent your sex partner(s) from getting HIV? (Check all that apply).

    a. Use condoms
    b. Take my HIV medicines regularly
    c. Partner takes PrEP (Pre-exposure prophylaxis/HIV prevention medication)
    d. (If inject drugs), I do not share needles, syringes or other drug equipment with partner
    e. My partner is HIV positive
    f. Does not apply—I do not have sexual partners.
    g. Other (please describe): _____

10. How many people do you know who are HIV+ and not using any HIV services?

11. Why do you think they aren't using any services?

12. How could HIV/AIDS care services be improved in Nevada?

13. Please tell us a little bit about yourself.

Gender:

☐ Female
☐ Male
☐ Transgender

How old are you?

_____ **years**

Zip code where you live:

Which race/ethnicity best describes you? (check all that apply)

☐ American Indian or Alaskan Native
☐ Asian
☐ Black or African American
☐ Hispanic or Latino/a
☐ Native Hawaiian or Pacific Islander
☐ White or Caucasian
☐ Other (please specify)

Sexual Orientation:

☐ Gay/homosexual
☐ Lesbian/homosexual
☐ Bisexual
☐ Straight/heterosexual
☐ Other (please specify)

Thank you very much for your time!

Appendix B: Twenty-four Services Listed in The Survey

Ten Medical Services:

1. Medical care

2. Dental care

3. Vision care

4. Mental health care

5. Specialty doctors

6. Therapy (occupational, speech, physical)

7. Nutrition help

8. Referrals to get other health care or services

9. Help getting off drugs or alcohol

10. Home healthcare

Fourteen Support Services:

1. Help paying for medicines

2. Help understanding medicines and how to take them

3. Help getting food

4. Help getting health insurance

5. Financial help

6. Transportation

7. Interpretation or translation into my language

8. Child care

10. Case management

11. HIV and health classes

12. Free condoms

13. Legal help

14. Support groups