PREVENTING THE SPREAD OF HIV AMONG HOMELESS YOUTH IN CALIFORNIA

by

Chinyere I. Iwuagwu

ROSSLYNN BYOUS, DPA, PAC, Faculty Mentor and Chair

GINA SPIVEY-BROWN, PhD, Committee Member

FAISAL ABOUL-ENEIN, PhD, Committee Member

Patrick Robinson, PhD, Dean, School of Nursing and Health Sciences

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789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

Abstract

The implications of nonadherence consistently show that nonadherence or poor adherence diminishes the efficacy of ART and have resulted in the increasing rate of hospitalization, mortality and morbidity among people living with HIV/AIDS despite advancement in medicine and science. The purpose of this study was to explore the phenomenon of adherence to HIV antiretroviral regimens among HIV-infected homeless youth in California. The goal of the study was to clearly understand the perception and perspectives of the issue of adherence from the standpoint of those closest to the individuals experiencing the phenomenon.

A renowned HIV/AIDS service organization in California was selected for the study, and the staff were interviewed. The findings from the study uncovered specific facilitators and barriers to adherence faced by homeless youth living with HIV/AIDS. The study established that one of the major differences between homeless youth and the general population was their attitude to HIV/AIDS; unfortunately, most of the homeless youth in California do not regard HIV as a serious health problem. The study also found that the most serious public health problems in the county where the research study was conducted were homelessness and substance abuse and as such some of the HIV infected youth sell their HIV medications to buy street drugs, while some who are lucky to be HIV-negative wished they were positive, so they could qualify for free housing and other free financial services.

The research study concluded that the quicker homelessness is addressed among youth living with HIV/AIDS the more realistic it will be to focus on medication adherence and ultimately focus on preventing the spread of HIV in California. The research study provides direction for future multifaceted study directed towards addressing the issues of homelessness, substance

abuse and prevention of the spread of HIV/AIDS among homeless youth living with HIV/AIDS disease as they are all interconnected and one cannot be solved without the other.

Dedication

This project is dedicated in loving memory of my late father Deacon Charles Chijioke Dinneya, who was violently taken away from this world four years before I started this journey. He would have been certainly proud of me embarking on this journey. I wish he was still alive to share in this accomplishment. Daddy, to me, you remain a role model and I know you must be proud of this accomplishment. I also know that you are smiling up there in heaven. My promise is that I shall continue to make you proud Adieu!

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CHAPTER 1. INTRODUCTION

Introduction to the Problem

Human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) continues to be one of public health's priority problems affecting the United States. HIV/AIDS has claimed more than a million lives since the epidemic began in the 1980s. Currently, it is estimated that about one in eight of the over 1.2 million people living with HIV in the United States are unaware that they are infected (Centers for Disease Control and Prevention [CDC], 2016b). Of this number, it is estimated that over one third to one half are either homeless individuals or individuals who are in imminent danger of being homeless (CDC, 2016b). Many studies have shown that the prevalence of HIV infection is about three times higher among homeless people than in the general population (Edwards, 2006).

Within the homeless HIV population, the subgroup of homeless youth presents a serious public health problem as the HIV epidemic continues to grow among this population. It is estimated that the prevalence of HIV within this population range from 2% to 11.5% (Edwards, 2006). The high prevalence of HIV within this population is primarily due to the engagement of homeless youth in several high-risk behaviors such as substance abuse/addiction, violence, and unprotected sexual activities thereby increasing their risk of contracting and spreading HIV.

Background of the Study

HIV is a disease, which if left untreated can progress to AIDS, which is considered the last stage of HIV disease. Prior to the invention of antiretroviral therapy (ART), HIV/AIDS was

widely perceived as a death sentence due to its significantly poor prognosis. However, with years of research, advances in medicine and treatment breakthroughs, HIV/AIDS is now considered more of a chronic disease that can be successfully managed with implementation of the appropriate blend of clinical interventions such as medications, diet modification and health care maintenance.

The introduction of ART in 1994 became a breakthrough moment for people living with HIV/AIDS (Edwards, 2006). ART has very positive effects on the lifespan and quality of life of individuals infected with the HIV virus (Richter, Michaels, Carlson, & Coates, 1998). The ART treatment helps to reduce the viral load of HIV and increases the CD4 cell count in infected people thereby helping to slow the progression of AIDS (Egger et al., 2002). Most importantly, ART medication results in a significant decrease in the morbidity and mortality of HIV disease (Edwards, 2006).

The use of the ART has been very helpful in controlling the spread of HIV/AIDS among homeless youth. It has also helped most youth living with HIV to live a relatively normal life. Adherence can pose a real challenge for most youth living with HIV. For ART to be as effective as expected in suppressing the HIV virus, an adherence level of 95% or greater is required (Bartlett, 2002). In addition, failure to maintain this 95% adherence level could lead to several adverse factors which includes progression of HIV to AIDS, and re-creation of HIV strains that are resistant to immune suppression drugs (Bartlett, 2002).

HIV/AIDS is a serious challenge to economic development, as it increases morbidity and mortality, reduces living standards, increases overall health expenditures for both medical care and social support and the repercussions affect all areas of the economy and the community (Haacker, 2004).

Statement of the Problem

Antiretroviral therapy has birthed a new hope for patients infected with HIV as these individuals are now living longer and healthier lifestyles. ART has made HIV/AIDS more manageable by slowing down the progression of the HIV virus and by reducing the occurrence of some of the opportunistic infections that make HIV/AIDS very deadly (Milloy et al., 2012). Adherence to ART is key to slowing down the progression of HIV disease. When infected individuals fail to adhere to their prescribed ART treatment it results in several health problems which includes increased risk for immune system failure and subsequent opportunistic infections.

Many studies have shown the impact of adherence and nonadherence to ART in the lives of HIV-infected individuals. Studies by Moss et al. (2004) and Milloy et al. (2012) showed that infected individuals who show faithful adherence to their prescribed ART medications have enjoyed healthier and more improved lifestyles. Conversely, studies have also shown that failure of people infected with HIV to adhere to their ART or treatment regimen has resulted in progression of their HIV status and resultant increase in mortality and morbidity (Gross, 2004).

One of the factors often cited for the high prevalence of HIV/AIDS among homeless youth is the problem of nonadherence. HIV-infected homeless youth develop serious health complications when they fail to adhere to their ART prescriptions. To gain a better understanding of this issue of nonadherence by homeless youth, it was very important to examine some of the factors that are barriers and facilitators of HIV nonadherence by the homeless youth population. Understanding these factors was very important for creating and managing the cases of homeless youth infected with the HIV virus. For HIV-infected homeless youth, treatment with ART is both a long-term and a lifelong commitment. Failure to maintain

the 95% adherence rate results in several problems which sometimes could be fatal (Bartlett, 2002).

Several categories of factors have been identified as being responsible for nonadherence to ART prescriptions by homeless youth. Per Rudy, Murphy, Harris, Muenz, and Ellen (2009), nonadherence to ART by infected individuals could be because of any of these three factors namely: —patient, medical, or system of care. Patient factors could be because of structural factors such as homelessness, which was the core of this study. This action research study used phenomenological approach to examine these factors responsible for none or low adherence to ART and other HIV treatments by homeless youth.

Purpose of the Study

There have been controversies over the attempt by some medical personnel to exclude HIV-infected homeless individuals from ART treatment based on the belief that these individuals will not be able to adhere to the strict regimen demanded by ART since homeless youth are known to lack stability, lack regular housing, lack regular access to food, water and other resources that are necessary to ensure adherence to antiretroviral therapy (Song, 1999). This failure to adhere to their ART treatment may cause them to develop some resistance to the medications; which will eventually limit their present and future treatment options (Song, 1999). Unfortunately, any attempt to exclude homeless youth from treatment will be counterproductive, as it will work against the effort to prevent and control the rate of HIV/AIDS among this population and within the general population.

Despite the difficulties facing homeless individuals in adhering to HIV treatment, homeless shelters and other service organizations that work with homeless youth have invested resources and time in trying to identify the most effective ways of delivering services and

providing follow-up resources for them. Treating homeless youth living with HIV presents very serious challenges for public health practitioners and for primary care providers. Despite the promises and optimism associated with ART in helping infected individuals manage their HIV disease, adherence continues to present very significant challenges for infected individuals. This challenge impacts homeless youth who live transient lifestyles making it difficult for them to keep up with the strict treatment regimen that ART demands. In addition, most homeless youth lack the needed support and resources to help them keep their medical appointments or adhere to their antiretroviral therapies (Audain et al., 2013).

Many factors exist as to why compliance with ART regimen can be challenging. Antiretroviral therapy has very low tolerance for missed doses and all patients on ART are expected to adhere strictly to the stringent rules regarding when patients must take the drugs and even when they must eat food. In addition, antiretroviral therapies require a higher level of adherence than most other medications (Garcia, Schooley, & Badaro, 2003). Most ART regimens have significant side effects. Such side effects include abdominal discomfort, nausea, vomiting, diarrhea, and headaches (Simoni, Frick, Lockhart, & Liebovitz, 2002).

Rationale

The purpose of this study was to explore the phenomenon of adherence to HIV antiretroviral regimens among HIV-infected homeless youth in California, by suspending all preconceived biases and prejudices about the subject matter. The goal was to clearly understand the perception and perspectives of the issue of adherence from the standpoint of either those experiencing the phenomenon or individuals closest to those experiencing the phenomenon. For this project, the researcher explored the phenomenon through the lenses of the individuals closest to those experiencing the phenomenon. Though the focus of this research was on homeless HIV-

infected youth, the primary participants in this research were 10 dedicated staff members of an identified service organization. These 10 individuals worked closely with the HIV-positive homeless youth. They counsel, support and provide them with essential services and are therefore proficient in sharing the lived experiences, knowledge, attitudes, practices and behaviors of the youth as it pertains to their adherence to HIV medications and/or other HIV treatment regimens.

It was the researcher's hope to formulate a set of interventional strategies, capable of engaging the homeless youth early in their infection and help them to continue or sustain their treatment. The study was geared to assist caregivers and health care professionals by enhancing their understanding of the complexity of adherence to HIV treatment by providing them with new insights on how to support the infected homeless youth.

Improving adherence to ART regimens by homeless HIV-infected youth will certainly have a tremendous impact on public health (Reisner et al., 2009) as it will help reduce the high mortality and morbidity rate among the homeless youth population. It will also help public health officials free up valuable manpower and resources dedicated to taking care of homeless youth. This will in turn allow for resources to be used towards other pertinent health and wellness needs of other communities they serve.

Improving adherence to HIV medications and treatment regimen will also result in a healthier population; this will consequently help to reduce the resources currently diverted to curtail the HIV/AIDS pandemic. In addition, improving adherence to HIV medications by the homeless youth will help reduce waste of resources and save valuable sums of money for both the public and the infected individuals.

This research was tailored to benefit both homeless youth living with HIV and their healthcare providers in dealing with the issue of adherence to medication. The knowledge gained from this research allows researchers to explore avenues to help homeless HIV-infected youth improve their adherence to ART treatments. In addition, reducing the rate and prevalence of HIV among the homeless youth will be beneficial to society, as it will help in the overall effort to control the spread of the disease. Numerous researchers have noted that homeless youth play a significant role in the spread of the HIV. This is because homeless youth in most cases participate in unprotected sex for economic reasons ("survival sex"), thus leading to the spread of the disease (Clatts, Davis, Sotheran, & Atillasoy, 1998).

In this research study, the researcher worked with a specific service organization to gain a better perspective on some of the barriers and facilitators of medication adherence by homeless youth in California. This project focused on improving the current practice, by working collaboratively with a service organization in California that devotes time and resources to the betterment of the homeless youth living with HIV/AIDS. This project used action research in collaboration with staff of a selected service organization to design HIV intervention strategies for homeless youth by (a) implementing measures for early testing, treatment and follow-up and (b) identifying and securing the necessary resources and support that will improve adherence to the prescribed treatment regimen for homeless youth.

It is hoped that the findings of this study will continuously provide additional resources for agencies, public health officials, health care providers, government, and non-governmental agencies working to reduce HIV/AIDS among the homeless youth population to improve the life and wellbeing of these youth through improving adherence to ART.

Research Questions

Guiding research questions for this project focused on factors responsible for the differences in adherence to ART and other HIV treatment interventions between homeless youth and youth living with HIV/AIDS in the general population. The research also proposed questions on factors responsible for poor adherence to medication by homeless youth and the relationship between homelessness and nonadherence to medication. These research questions were framed in the following way:

1. What are the perceptions of HIV-infected youth experiencing homelessness regarding adherence to HIV medications or any other HIV treatment regimen?
2. Excluding homelessness, what other lived experiences/factors of the homeless HIV-infected youth are responsible for poor adherence to HIV medications or any other HIV treatment regimen?
3. Are there differences in the rate of adherence to HIV medications or any other HIV treatment regimen between the lived experiences of homeless HIV youth and their counterparts in the general population?

These research questions guided the research in gaining a better understanding of the factors responsible for poor adherence to ART by the homeless youth. The answers to these research questions also guided the research in gaining a better understanding of the factors responsible for poor adherence to ART by the homeless youth. The answers to the research questions also helped the researcher to gather evidence in knowing whether the assumptions made at the start of the research were correct or incorrect.

Significance of the Study

Adherence to the strict regimen of antiretroviral therapy has been a major challenge for most people living with HIV/AIDS (PLWHA). According to Shubber et al. (2016), it is still a puzzle that despite more than two decades of research on adherence to ART and even though more than 17 million HIV-positive people rely on ART for their treatment, adherence has continued to pose a significant challenge.

Within the very subgroups of infected people on antiretroviral therapy, adolescent HIV patients have the greatest difficulty adhering to their ART regimens (Palepu, Milloy, Kerr, Zhang, & Wood, 2011; U.S. Department of Health and Human Services, 2016). This poor adherence to ART has resulted in homeless youth having poorer quality of life and higher mortality rates when compared to other populations living with HIV/AIDS (Milloy et al., 2012). While the advent of antiretroviral therapy has quickened the recovery rate of most people living with HIV, the recovery of most homeless youth has lagged because of their poor adherence to their HIV treatments (Palepu et al., 2011).

This challenge becomes more pronounced among homeless youth who are faced with a myriad of other issues that make adhering to medications insignificant to them. Homeless youth do not only have problems with adhering to their medications, they also have difficulty keeping up with their medical appointments (Adler, Herman, & Susser, 2005). Their transient lifestyle makes it difficult to track them and render the necessary support and resources that they need including monitoring their antiretroviral therapy. According to the National Coalition for the Homeless (2007), adherence to medical regimen by homeless youth is a very serious issue with both personal and public health implications.

Currently, public health officials rely on shelters for contact and treatment of homeless youth. This practice is fraught with challenges as most of these shelters are poorly staffed and they find it almost impossible to keep up with the homeless youth and their treatment. Most homeless youth lack the facilities to store their medications (Palepu et al., 2011), most of them are transient and are constantly on the move and thus lack the privacy necessary for them to keep up with their medications (Rotheram-Borus, Koopman, & Ehrhardt, 1991). In addition to the above factors, there is also the stigma attached to being HIV-positive, the side effects associated with most HIV medications and some personal, social, and psychological issues that make adherence to their medication an added challenge.

To address these issues, several interventional strategies have been recommended by researchers. According to Reisner et al. (2009), the most common forms of intervention used by most healthcare providers to address these issues are education, counseling, use of telephone reminders, and rescheduling or reducing medication dosage. While these interventions have been helpful, they have not been totally successful as these barriers to adherence among HIV infected homeless youth population group persist. There is therefore a need to implement interventional strategies that could help to boost the rate of adherence to HIV medications in general and ART within the population group. This research study was intended to do just that. It was intended to provide additional resources for healthcare providers to be used in identifying and designing better interventional strategies for HIV-positive homeless youth.

Many researchers have shown that no single intervention will be sufficient to ensure high levels of adherence to HIV medication by homeless youth living with HIV. To guarantee that this population sustains high levels of adherence, some key improvements are required. It is necessary to consider a triaged approach that will not only identify the patients at poor risk of

adherence but will also seek to identify and establish the appropriate types of support that is needed to overcome the most important barriers to adherence (Reisner et al., 2009).

Definition of Terms

Throughout this study, several terms will be used that may need defining to avoid ambiguity to readers. Therefore, readers are provided the following definitions of terms to make for better understanding of the study.

Acquired Immunodeficiency Syndrome (AIDS). This refers to the late/final stages of HIV, which results due to lack of treatment. AIDS is that stage where the immune system is damaged and susceptible to several diseases and HIV related cancers. At this stage, the body needs medical intervention to prevent death. According to the CDC (2016a), AIDS is the last stage of HIV infection because the immune system is so severely damaged warranting a barrage of severe illnesses, called opportunistic illnesses. AIDS diagnosis is validated when a person's CD4 cell count drops below 200 cells/mm and or if the person develops certain opportunistic illnesses due to the weakened immune system. People with AIDS can have a high viral load (these viral loads represent the number of viruses in a HIV/AIDS patient system/body) and be very infectious (CDC, 2016a).

Adherence. To stick to. In relation to people living with HIV/AIDS, *adherence* refers to adherence to HIV/AIDS medications and treatments. It means a commitment to taking HIV/AIDS medications every day as ordered (National Institute of Health, 2016). Strict adherence to HIV/AIDS treatment regimen prolongs the lives of those living with HIV/AIDS.

Highly Active Antiretroviral Therapy (HAART) and Antiretroviral Therapy (ART). Combination of at least three different antiretroviral drugs that are used to stop the HIV virus from multiplying (National AIDS Resource Center of Ethiopia, 2017). Treatment with these

combinations drugs is also known as ART. HAART and ART are often used interchangeably. The successful use of ART has reversed a known deadly disease to a manageable chronic condition. Although not a cure, HAART/ART suppresses HIV viral replication and prolongs the quality of the lives of PLWHA (people living with HIV/AIDS). However, once HAART/ART is initiated, strict adherence is required.

Human Immunodeficiency Virus (HIV). A virus that destroys the body's immune system, specifically the CD4 cells (T cells). These cells are called the body's helper cells and are responsible for defending the body. They act like armies and help the body to fight off diseases and infections. Therefore, if HIV is left to attack and destroy the body without any treatment, these helper cells in turn diminish in number and become unable to carry out their functions of warding off diseases and infections and thereby render the body immune-suppressed—meaning a weak immune system that leaves the body susceptible to several diseases and HIV related cancers. Untreated HIV will lead to AIDS.

Assumptions and Limitations

Assumptions

The study had three key assumptions:

1. Transient lifestyle prevents adherence. Transient lifestyle of homeless youth has been a major contributory factor to their nonadherence to the HIV treatment regimen. This nonadherence or poor adherence has made worse an already bad situation among this population, thus resulting in high mortality and morbidity rates due to HIV/AIDS within the population group.
2. Knowledge improves adherence. The study also assumes that the knowledge and information gained from this study particularly on the challenges and strategies for

improving ART and other HIV treatments adherence by the homeless youth will be beneficial not just for the youth themselves but for healthcare providers and public health practitioners in general.

3. Appropriate resources improve adherence. The research also assumes that despite the vulnerability of the homeless youth, when given the right atmosphere, resources and encouragement they could be motivated to take responsibility for their own well-being.

Limitations

The study had the following six limitations:

1. Recruitment and interview of study participants from a single organization.
2. Non-guaranteed commitment of the service organization.
3. Interviewing the providers and not the patients.
4. Non-existent gold standard for measuring optimal HAART medication compliance and adherence.
5. The researcher being a nurse and having prior knowledge of HIV/AIDS.
6. The small sample size utilized in this research.

Theoretical Framework

The theoretical framework of this research study was based on Orem's (1971) theory of self-care as well as the readiness to change model otherwise known as the transtheoretical model (TTM). Orem's theory was developed by Dorothea Orem, a U.S.-born nurse who published her nursing theory of self-care in a book titled *Nursing: Concepts of Practice* in 1971 while the concept of TTM was developed by James Prochaska and Carlo DiClemente in 1992. Orem's theory of self-care is rooted on the concepts of information, knowledge, self-reliance and

personal responsibility. This research explored how infected homeless youth could benefit from the use of information and knowledge to improve their adherence to ART and other forms of HIV interventions. The goal was to use the knowledge of the existing barriers, consequences and solutions gained during the research to alter their behaviors about adherence to HIV interventions.

On the other hand, Prochaska and DiClemente's 1992 study of the TTM coined the terms for the five stages of change and the 10 processes that assists in changing behavior (Pender, Murdaugh, & Parsons, 2001). TTM proposes that intentional behavioral changes related to health occur in stages; movement, from one stage to the next, is accomplished by building upon the successes of the prior stage (DiClemente, 2007). The stages of TTM are as follows:

1. Pre-contemplation: No immediate plans to make a change. Possible denial that a problem exists. Possible new-found interests in a problem or solution.
2. Contemplation: Concerns about the consequences of maintaining the status quo versus adopting new behaviors. May consider behavioral change(s) in the next six months.
3. Planning/Preparation: Thinking about making a commitment to change. Planning the pursuit of a behavioral change that is likely to occur in the next month.
4. Action: A shift to the new behavior. Engagement in the change plan and establishment of a new pattern of behavior.
5. Maintenance: Sustenance of the new behavior. Integrating the new behavior as a habit into one's normal lifestyle. The new behavior is maintained over a period.

The processes of change focus on the individual's coping activities (DiClemente, 2007) and the individual's perceived pros and cons of adopting new behaviors versus maintaining current practices (Glanz, Rimer, & Lewis, 2002). The 10 processes are as follows:

1. Consciousness raising
2. Dramatic relief
3. Environmental reevaluation
4. Self-reevaluation
5. Social liberation
6. Stimulus control
7. Helping relationships
8. Counter conditioning
9. Reinforcement management
10. Self-liberation

These processes help practitioners to gauge change strategies that are appropriate to the current state of readiness to change, and to the individual's personal values, spirituality, culture, and physical needs (DiClemente, 2007).

Organization of the Remainder of the Study

The remainder of the study consisted of the following four chapters: Chapter 2 presented a detailed review of pertinent literature related to HIV/AIDS, homelessness, and ART adherence. Chapter 3 provided insights about the methodology; the qualitative research design that was used to examine the study and to analyze the data. Chapter 4 provided an analysis and an interpretation of the data collected. Chapter 4 also displayed a demographic overview of the studied population, and presented the results of the interview with findings. Chapter 5 concluded

the study by providing recommendations for future research studies as well as pointed out the implications of the study's findings.

CHAPTER 2. LITERATURE REVIEW

Introduction

In seeking to understand adherence to HIV treatment from the perspective of homeless youth, the author examined the current literature on HAART adherence. The literature review focused on the following areas: the distinction between adherence and compliance, the barriers and facilitators of adherence to HAART by PLWHA, the relationship between homelessness, HIV adherence and the correlation between youth adherence and HAART. Search terms were *homelessness*, *homeless youth living with HIV*, *homelessness and adherence*, *youth and adherence*, *measuring adherence*, *improving adherence*, *interventions to improve adherence*, *adherence*, *compliance*, *compliance versus adherence*, *barriers to adherence with antiretroviral therapy*, *adherence to antiretroviral therapy*, *improving adherence*, and *facilitators to antiretroviral therapy*.

The last two decades have witnessed major shifts in the fight against HIV/AIDS and advances in the field of medicine and pharmaceutical sciences have given rise to ART and other combinations of antiretroviral drugs which have transformed HIV/AIDS from a fatal diagnosis to a very manageable chronic illness. The antiretroviral therapy has become the only hope for prolonging the lives of PLWHA; living healthy and meaningful lives without the fear of opportunistic infections (Hogg, Yip, Chan, O'Shaughnessy, & Montaner, 2000).

Despite the promises of HAART in saving and prolonging the lives of individuals living with HIV/AIDS, the rate of patients' adherence to this treatment regimen has left much to be

desired. HAART has very strict and unforgiving regimens, which patients must adhere to for them to get the desired optimal result from the medications. For example, HAART prescription requires that patients on the regimen adhere religiously to their prescriptions without missing any dose. People on HAART prescription are expected to maintain a 95% adherence to get the full benefit of their prescription (Bartlett, 2002). If a patient on HAART fails to take their prescription or takes their doses improperly, they run the risk of developing resistance to the drugs contained in the regimen and thereby could result in clinical failure (Bartlett, 2002).

In some cases, when HIV-positive individuals develop drug resistance based on poor adherence to their ART regimen, they run the risk of transmitting the drug resistant strain of HIV to other individuals which often lead to an epidemic of untreatable forms of the HIV (Hecht et al., 1998). It is for this and for a host of other reasons that adherence to ART is very important. Per Roberts (2005), adherence to antiretroviral regimen is not only important for the health of the HIV-positive individuals but also very important when considering the health perspective of the public in general.

Adherence Versus Compliance

The terms *adherence* and *compliance* are often used interchangeably in some medical journals and articles (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Even though the term adherence is gaining acceptance in the medical community, there is still no established distinctive definition between the two terms. The term *adherence*, according to the *American Heritage Dictionary* (1994), is defined as the ability of a patient "to follow closely; carry out without deviation" (p. 13). This *American Heritage Dictionary* definition of *adherence* is similar to the definition of *compliance* in some articles and journals. Horne, Weinman, Barber, Elliot, and Morgan (2005) define compliance as the "extent to which the patients" (p. 12) behavior

matches the prescriber's recommendations. This definition denotes a relationship between patient and the clinician, where the clinician has the responsibility of deciding the appropriate treatment while the patient passively follows the clinicians order.

It does appear that the major area of difference between the term adherence and the term compliance is the extent of patients' involvement. Frain, Bishop, Tschopp, Ferrin, and Frain (2009) relates adherence to an agreement between a patient and a doctor, they define adherence as the extent to which a patient follows a treatment plan agreed on by both the patient and the provider. The key word is the term *agreement*. On the other hand, compliance seems to imply total obedience by the patient. To that end, adherence implies that the patient is free to decide whether to follow the provider's recommendation or not and as such, failure of the patient to keep up with the doctor's prescription should not be blamed on the patient.

Vermeire et al. (2001) sees a problem with the term *compliance* because it attributes too much power to the clinicians, they believe that the term adherence reduces the perceived power attributed to the clinicians. In recent literature, many researchers prefer to use the term adherence because they view the concept of compliance as an outdated concept, which portrays the patient as deviant, willful, stupid or ill informed (Steward, 2005). It does appear that the growing acceptance of the term adherence stems from the association of the concept of compliance with total and passive obedience by a patient.

Adherence to Antiretroviral Therapy

The invention of ART and other highly effective antiretroviral therapeutic agents over two decades ago has marked a milestone in the fight against HIV/AIDS (Song, 1999). These therapeutic agents have shown that they are very effective in suppressing the progression of HIV

virus in infected individuals (Song, 1999) and in decreasing the rate of morbidity and mortality for people living with HIV/AIDS (Edwards, 2006).

Biomedical research has also led to improvement in the various tests used to measure the progression of HIV in infected individuals. Today, clinicians can calculate the number of viral loads in the blood plasma of infected individuals. Biomedical researchers have also determined that in some cases, several antiretroviral agents combined have greater potential of reducing the viral loads of infected individuals to undetectable levels in a very short time period (Song, 1999).

Despite the promises associated with antiretroviral therapies in controlling and suppressing HIV, it has often been very difficult to get HIV patients to adhere strictly to their treatment regimen. The ART regimen requires strict and complicated adherence by patients for optimal effectiveness. Several years ago, patients on ART were usually required to take more than 20 pills per day and follow a strict dietary requirement (Song, 1999). Today patients no longer take as many pills; some patients taking ART regimen still experience severe adverse side effects from the medication. These and other factors have often led to the problem of low adherence to ART regimen.

Per Reynolds (2004), difficulty in taking medication by people living with HIV/AIDS has been one of the most significant factors affecting patients' adherence to their HAART regimen. Given the problems associated with non-/low adherence to ART by infected people, the issue of adherence has become a major public health challenge which deserves urgent attention. According to Cote and Godin (2005), successful ART treatment requires a near perfect 95% patient's adherence to prescribed regimen (Bartlett, 2002). Suboptimal adherence to ART results in several problems including rapid development of medication-resistant strains of HIV. When compared with other illnesses, it is easy to see that HAART has a very high bar for adherence.

For example, while tuberculosis requires only 80% adherence level for optimal effect, individuals taking HAART are required to maintain an adherence level of 95% or greater (Cote & Godin, 2005) for optimal effect. This is what makes HAART unique compared to other therapies for other illnesses. While some other illnesses can tolerate an adherence of between 70% and 80%, a HAART adherence rate below 70% or 80% have been associated with patients developing drug resistant strains of the HIV (Cote & Godin, 2005).

Several problems have been associated with poor adherence to ART including patients developing drug resistant strains of HIV, which in turn precludes them from adequate treatment (Levine et al., 2005). Furthermore, a review of the current literature centered on HIV medication adherence, Frain et al. (2009) found that HIV individuals with an adherence rate of less than 70% rarely show improvement in their viral markers and in most cases, they develop drug resistant strains of HIV.

HAART is a lifelong and a long-term treatment for patients with HIV (Genberg, Lee, Rogers, & Wilson, 2015). It is therefore very important to understand some of the factors that could be barriers or facilitators to patients' adherence. Knowledge of some of these factors could be very helpful for public health officials in designing effective interventions to best promote and maintain adherence. Hogg et al. (2000) studied the relationship between HAART adherence, and other variables. Their study showed a startling correlation between HAART adherence and mortality of individuals living with HIV/AIDS. Their study showed that a 10% decrease in adherence, increased mortality by 16%.

Chesney (2000) studied and grouped factors influencing adherence to HAART by people living with HIV into four groups: (a) patient factors, which include drug use, alcohol use, age, sex or ethnicity; (b) medication regimen such as dosing complexity, number of pills, or food

requirements; (c) patient–healthcare provider relationship; and (d) the system of care. Other researchers also found various other reasons for nonadherence. Mills et al. (2006) conducted a systematic review of previous studies to examine the concerns of HIV patients to maintaining their HAART adherence. Their study found that fear of disclosure, forgetfulness, a lack of understanding of treatment benefits, complicated regimens, and being away from their medications were consistent barriers to adherence across developed and developing nations. HAART also causes some unpleasant side effects to positive patients. These side effects identified as barriers to adherence include diarrhea, nausea and neuropathy (Fogarty et al., 2002).

Review of Existing Literature

Adherence to medications is a major public health problem and it imposes a very heavy financial cost on both individuals and the society at large. In the United States, adherence to medication is estimated to cost over $100 billion yearly (Braithwaite, Shirkhorshidian, Jones, & Johnsrud, 2013). According to Vermeire et al. (2001), adherence to medication is an ever present and complex problem for patients with chronic illness.

The problem of adherence to antiretroviral therapies is not just a U.S. problem, but also a worldwide problem. According to Weiser et al. (2003), the average range of patients' adherence to their ART is between 50% and 70%. This figure is consistent across different social and cultural settings. This figure is below the 95% or higher rate that is necessary for optimal performance of ART in the infected individuals. In most developing countries in the world including Botswana, where Weiser et al. did a study on the barriers to ART adherence; availability and cost of highly antiretroviral therapy were identified as the major problems to HIV/AIDS management. However, in the United States, while ART medications are readily available and affordable, the major problem to control the epidemic is the issue of patient

adherence. Presently, there is a large body of literature examining the barriers, facilitators and correlates of adherence by PLWHA in the United States.

Mills et al. (2006) conducted a comprehensive analysis of 84 previous studies on HAART adherence in the United States. Their study identified four major themes of patients reported barriers to HAART adherence. These themes include patient-related barriers, patients' beliefs about medication, problems with daily schedules and patient's interpersonal relationships. Additional patient-related barriers included fear of disclosure, feeling depressed, hopeless or overwhelmed, having a concurrent addiction problem, forgetting to take medications, being suspicious of treatment/medical establishments, financial constraints and being homeless. The study also identified the following problems related to patient's beliefs about medications as some of the barriers to patient's adherence, they included side effects, complicated HAART regimens, pill count, taste, size, dosing frequency, doubting the efficacy of HAART and having decreased quality of life.

In a nutshell, the studies identified nine common barriers related to daily HAART schedule. These barriers include disruptions in routine, difficulty incorporating HAART into daily schedules, difficulty coordinating adherence with work or family, difficulty balancing dietary requirements, being busy or distracted, being away from home, and so many other reasons. Finally, the study identified the following problems associated with the patient's interpersonal relationships. This included lack of trust or dislike of caregiver, negative publicity regarding HAART, social isolation, and discouraging social networks.

Frain et al. (2009) believes that self-reporting by patients is one of the most reliable ways of measuring patients' adherence to HAART regimen. Their study of self-report by 76

individuals living with HIV found the following factors necessary for improving adherence by patients living with HIV/AIDS:

1. Patients being certain of their course of treatment.
2. Patients having more trusting relationships with their medical providers.
3. Patients with family resources.
4. Patients with more optimism for life.

Genberg et al. (2015) also examined self-reported barriers to adherence among patients taking ART. Their study analyzed the different types of barriers identified by patients and how these barriers were correlated. They found that self-reported barriers by patients remained the same over time and that all the different types of self-reported barriers were associated with reduction in patients' adherence to their HAART.

ART is a lifelong complicated endeavor, which requires faithful adherence for optimal results. Some patients plunge into the ART regimen without being adequately educated or prepared for the complicated nature of the regimen. According to Grimes and Grimes (2009), the poor adherence of patients to ART regimen is related to lack of readiness before the HAART is prescribed for them. Their study concluded that most clinicians are not good at judging patient's adherence to HAART regimens.

Ammassari et al. (2002) reviewed 20 previous studies on the barriers to ART adherence by people living with HIV/AIDS. Their study showed that various studies on HAART adherence have yielded discordant notes on the barriers to adherence. Ammassari et al. found symptoms, adverse effects, psychological distress, lack of social or family support, complexity of HAART regimen, low patient self-efficacy, and inconvenience of treatment as factors consistently associated with poor adherence. However, Ammassari et al. found that the literature was

inconsistent in their conclusion regarding the relationship between adherence and such variables as sociodemographic characteristics, substance abuse, depressive symptoms, quality of life, CD4+ cell count, knowledge and beliefs about treatment, patient's satisfaction with healthcare, and patient–provider relationship.

Reynolds (2004) studied the adherence of patients to medication. They found that most patients do better with their adherence when they know the medications and the purpose of their treatment. This study found that patients have more likelihood of adhering to their medications when they believe that their treatments are necessary and effective and when they believe in their ability to go through the rigorous ART regimen. Whereas, Mannheimer et al. (2005) examined the relationship between quality of life and adherence to ART regimen. Their study found significant association between adherence and quality of life. They found that patients with higher and better adherence showed a higher scale of quality of life when compared to patients with poor adherence to the HAART regimen.

Barriers to Adherence

There have been and still exists a large body of researchers examining many factors that are barriers and predictors to patients' adherence to ART. Genberg et al. (2015) in their study identified four types of self-reported barriers to adherence: medications and health concerns, stigma, family responsibilities, and problems with schedule and routine.

Rudy et al. (2009) classified the factors influencing patients' adherence to ART regimen into three categories: patient factors, medication factors, and system of care. According to Rudy et al., the patient factors can be further divided into three categories as follows: behavioral factors related to outcome expectancies regarding the effectiveness of ART, mental health and substance abuse, and structural barriers such as homelessness.

Another study to evaluate ART adherence problems was conducted in Nepal, India, by Wasti, Simkhada, Randall, Freemans, and Teijlingen (2012) the study grouped the major barriers to ART adherence into five interwoven themes:

1. Economic—Financial restraints
2. Patients' beliefs and behaviors—Perception about ART and substance misuse
3. Sociocultural—Lack of family support, stigma, and discrimination
4. Health care provision and system—Distance, short period of medicine prescription
5. Drug related barriers—Side effects, strict and structured regimen

Stigma

Even though, HIV/AIDS disease has been in existence for some decades, it remains a highly stigmatized-disease. This stigma associated with HIV/AIDS cuts across settings and countries. Because of this stigma, PLWHA suffer a lot of discrimination due to their health status. This stigma often stands in the way of infected people adhering strictly to the antiretroviral therapies. Sayles, Wong, Kinsler, Martins, and Cunningham (2009) and many others studied the effect of HIV related stigma on patients' adherence to the HAART regimen and their studies concluded that HIV stigma may be associated with suboptimal ART adherence.

Sweeney and Vanable (2016) reviewed 37 quantitative studies on HIV-related stigma and medication adherence and majority of the studies identified stigma and medication adherence as a major problem with the population of youth living with HIV/AIDS. Their study found that despite the great strides made in improving the lives of PLWHA, that the stressors encountered by PLWHA because of the HIV/AIDS stigma have been a major barrier to patient adherence to HAART regimen. They found that the social stigma associated with HIV/AIDS sometimes makes it difficult for PLWHA to take their medications in public places and therefore concluded

that fear and anxiety of people becoming aware of their HIV status could result in skipped or delayed doses.

Interventions to Improve Adherence

Some researchers have identified forgetfulness as one of the reasons for poor adherence by patients taking ART prescriptions and as such different studies have proposed distinct interventional strategies to improve ART adherence. Researchers have suggested the use of reminder devices (Wu et al., 2006), case management (Kushel et al., 2006) and electronic monitoring (Lewis, Colbert, Erlen, & Meyers, 2007) as effective ways to improve patients' adherence to ART regimen.

Homeless individuals often live complicated and nomadic lifestyles, which often result in forgetting to take their medication at the scheduled time. Wu et al. (2006) conducted research on how to help PLWHA to overcome the obstacle of forgetting to take their HIV medications with the use of reminder devices. In their study, Wu et al. examined the effectiveness of using reminder devices to verbally remind patients to take their medication(s) at the proper time and electronically record the doses taken. Their study found that while these devices appeared to improve adherence, the overall quality of life for the subjects using the devices decreased.

Roberts and Mann (2000) identified mechanical devices, routinizing, health beliefs and making commitments as possible facilitators of ART adherence. His reasoning is that patients are more likely to adhere to their ART prescriptions when they have mechanical devices like the alarm clock to remind them, when they understand the strict requirement of 95% adherence demanded by ART, make personal commitment to keep to it and have a clear understanding of their ART schedule. In addition, he believes that patients' belief that the ART will work is a major facilitator of their adherence.

Kushel et al. (2006) suggested the use of case management to facilitate ART adherence. They did a study to determine the effectiveness of using case management to improve adherence by infected people. These group of researchers found that the use of case management could help to improve adherence to ART among infected homeless and marginally housed individuals. They also found that case management was independently associated with improved adherence to ART and improved CD4 cell count.

Chesney (2000) believe that clinicians can play a very important role in facilitating adherence by patients. Chesney suggested that clinicians could tailor their choice of drug regimen to suit the patient's lifestyle. In addition, Chesney stated that the use of reminder calls, alarms and frequent follow-up when initiating or changing drug regimens as well as extended consultation time to explain and reinforce medication instructions gave rise to huge success stories.

On the contrary, some researchers have also argued that no one method of intervention can achieve about 95% adherences to ART by infected people. After reviewing 16 previous studies on interventions to improve ART adherence, Cote and Godin (2005) concluded that for interventions to be effective, a multifaceted approach involving a multidisciplinary team needs to be used. This view was supported by Genberg et al. (2015), whose group of researchers also emphasized the need for an intervention tailored towards a multidimensional approach regarding ART adherence. Genberg et al. stated that because barriers to adherence are multidimensional, providers must also utilize a multidimensional approach in finding solutions. This is warranted because providers often assess one or two given factors at the expense of delving into and addressing the major concern of the patient.

Measuring Adherence

The questions often asked in determining patients' adherence to ART regimen are how, what and when to measure? According to Ammassari et al. (2002), there is no gold standard for assessing adherence among patients. Chesney (2000) agreed that adherence to ART is difficult to measure; however, Chesney went on to identify four basic techniques for quantifying adherence: patient self-report, report of missing pills, assays of drug levels, electronic monitoring systems, and many more.

In fact, different methods of assessment have been used to determine patients' adherence to their ART regimen. These assessment methods included patient self-report, physician estimate, review of pharmacy records, pill counts, electronic monitoring devices and plasma drug levels (Walsh, Dalton, Gill, Burgess, & Gazzard, 1988), self-report of pills missed, pill count, recording from devices of times and dates of bottle openings, prescription refills, and blood or urine biological assays (Wilson, Hutchinson, & Holzemer, 2002). Contrarily, Vermeire et al. (2001) argued that the complex nature of ART adherence has made it difficult for researchers to develop a gold standard method of measurement. This group argued that the lack of a valid method of measuring ART adherence remains a major barrier to research on adherence.

Among the various adherence assessment methods, Vermeire et al. (2001) believe that use of patients/provider's interviews and patient self-reports are methods vulnerable to overestimation of medication compliance and underestimation of noncompliance. Self-reporting which is about the most widely used form of measuring adherence is subject to overestimation. On that note, Bangsberg et al. (2001) studied a cohort in San Francisco made up mainly of individuals from homeless shelters, and free-lunch programs to determine the accuracy of providers assessments of adherence to ART in that population. They realized that both patients

and provider's overestimated adherence (when compared to pill count). They also learned that providers' estimates of individual patient adherence to ART were poorly associated with adherence measured by unannounced pill count.

Homelessness and Adherence

Homeless individuals are one group of individuals most vulnerable to HIV/AIDS. According to Song (1999), the prevalence of HIV/AIDS is higher among homeless people than in the general population. Some of the conditions associated with homelessness make HIV prevention and control more difficult to manage than among other populations living with HIV (Song, 1999). Not only do homeless people have limited access to medical care, their living conditions make it very challenging for them to stick to the strict demands of ART regimen.

Kidder, Wolitski, Campsmith, and Nakamura (2007) investigated HIV medication adherence among housed and homeless people living with HIV. They found homeless participants had lower CD4 counts. They also learned that homeless people were less likely to have taken antiretroviral medications and were also more likely to adhere poorly to their HAART regimen. Wolitski, Daniel, and Fenton (2007) found that homeless patients have a greater risk of poor adherence and advised that to improve the rate of adherence among this population healthcare providers should routinely assess and encourage adherence. In addition, they also advocated that healthcare providers must work with these individuals to develop strategies for achieving and maintaining high levels of adherence.

Youth and Adherence

Studies regarding barriers to adherence to ART by homeless youth have shown a similar pattern to what was seen in other homeless population. This matter is made worse by the unique barriers that face homeless youth. Palepu et al. (2011) in a long term prospective study of HIV-

infected intravenous drug users did a comprehensive study of HIV infection among homeless youth and found that individuals who are unstably housed or homeless have higher rates of HIV/AIDS infection when compared with individuals who are housed. Their study identified several barriers to adherence among homeless individuals. The barriers identified include poor access to regular meals and water, lack of a fixed daily routine, no place to store medications and lack of privacy. Roberts (2005) identified another six barriers to adherence among infected youth:

1. Family daily routine
2. Medication side effects
3. Medication taste, size, and shape
4. The stigma of HIV/AIDS
5. Medications as a reminder of HIV/AIDS

According to Arnett (2004), a normal part of the developmental process from adolescents to young adults frequently involves a lot of risk taking. These risks taking includes behavioral experimentations involving alcohol and drugs use, as well as adventurous sexual exploits. The literature indicates that nonadherence is more prevalent in some specific populations such as injection drug users, patients with mental problems, women, and homeless individuals. However, Shubber et al. (2016) concludes that maintaining high levels of adherence to ART is a challenge across settings and populations.

In their review of 21 published studies focusing on adherence to ART and other forms of intervention by infected youth, Reisner et al. (2009) states that antiretroviral medications allow HIV-infected adolescents and young adults to manage their HIV infection as a chronic condition rather than as an imminently life-threatening disease. They found several studies, which

associated young age with nonadherence to ART. They concluded that the most promising strategies for improving treatment adherence among HIV-infected youth involved patient and caregiver education, self-monitoring, peer support, and telephone follow-up.

Rudy et al. (2009) believes that nonadherence to ART is a major barrier to successful treatment of HIV-infected youth. In their studies of the problem of nonadherence among HIV-infected youth in the United States; they concluded that adolescents have multiple personal barriers, which have often resulted in significant rates of nonadherence to ART. They believe that knowing how age impacts adherence and subsequent viral load suppression could inform policy development resulting in programs that more effectively target younger members of this vulnerable population.

Rodriguez et al. (2003) studied 283 patients taking HAART medications to determine the clinical and demographic variables related to HAART adherence. Patients were asked about variables concerning age, educational level, labor situation and family status. Their study concluded that younger patients taking a high number of ART agents, and those showing noticeable anxiety levels required special attention to improve adherence. Another group of researchers, Rotheram-Borus et al. (1991) stated that the delivery of HIV treatment for infected youth is more difficult than in any other age groups because of several life stressors such as living situations, and adjustment problems of these youth. In another study, Lightfoot, Rotheram-Borus, and Tevendale (2007) studied HIV adherence across age levels and determined that younger individuals living with HIV had greater tendency to be nonadherent than older people.

Gaps in Existing Literature

Many literatures studied the factors influencing adherence to ART among individuals living with HIV/AIDS. While the literature studied the concept of adherence and some of the

tools needed to measure adherence, a gap still exists in the understanding of the concept of adherence, especially as it applies to homeless youth who are the subject of this study.

Cote and Godin (2005) performed a critical review of some studies on interventions designed to enhance patient's adherence to ART. They reviewed a total of 16 previous studies that were designed to evaluate strategies to enhance patients' adherence to the HIV/AIDS regimen. These 16 studies targeted various population groups including general HIV population (7), active intravenous drug users (4), substance abuse patients (2), women (1), and an underrepresented population (1). Surprisingly, none of these studies pointed to a specific group being most at risk for nonadherence.

Effective interventions in improving ART adherence is certainly another important area that needs more study to reach a resolution. According to Cote and Godin (2005), only a few pilot studies have reported data suggesting that interventions could be effective in promoting adherence. Genberg et al. (2015) states that there is need for more qualitative research to examine how self-reported barriers to ART adherence relate to one another and how they can differentially predict measured adherence. Chesney (2000) states that the first step toward addressing the problem of medication nonadherence is to accurately identify patients whose risk of nonadherence is sufficient to undermine clinical outcomes.

Theoretical Foundation

One major assumption of the Orem's (1971) theory is the belief that people should be self-reliant and therefore should be able to take care of themselves and others in their family. It is this assumption of individual responsibility that will motivate the homeless youth to take responsibility for their health. To participate in the action research study and reap its full benefits, the homeless youth must take responsibility for their health and that of others in their

community. The participants will show their realization that continued poor adherence to HIV medication within the community will only lead to more unhealthy youth population and an increased rate of mortality.

Another assumption of the Orem's (1971) theory which has bearing on this research study is the assumption that knowledge of healthcare problems is a necessary factor for people to initiate or promote self-care behaviors. It is based on this assumption, that the action research study involved education and training of the youth on the barriers, and benefits of adhering to ART and other HIV medications. Thirdly, Orem's theory also assumes that self-care is learned within a social context. People usually copy from their mates, friends, mentors and people of their social group. It is based on this assumption that some staff members of the service organization researched for this study use themselves as an example for their clients to emulate.

On the other hand, the concept of TTM evaluates a person's willingness to adopt a healthier lifestyle while providing strategies to lead the person through the phases of change to action and sustenance. TTM is an effective tool and applicable to assist in predicting several maladaptive health behaviors such as alcoholism, substance abuse, smoking, sexually transmitted diseases, screenings for diseases, medical regimen compliance and many more. TTM remains a consistent framework used by the practitioners of the service organization inferred in this study to study change behavior patterns, actions, and perceptions of their numerous homeless HIV-infected clients who are moving along the change continuum. The use of this model empowers the providers of the identified service organization in identifying and planning interventions that are currently assisting their clients to adopt health promoting behaviors as an effective approach to wellness and recovery treatment planning.

CHAPTER 3. METHODOLOGY

Research Design

The research was carried out using qualitative phenomenological research method with the goal of accurately describing the essential meaning of the homeless youth lived experiences in relation to their HIV management and medication adherence. The purpose of the phenomenological approach was to clearly illuminate the specific; to identify the phenomena from the perspective of the individual actor or the group in a situation (Van Manen, 1990). According to Lester (1999), phenomenological approaches are known to uncover deep issues, make voices heard and as such unveil "taken for granted assumptions" (p. 1).

The use of qualitative methodology was appropriate in establishing causal relationships including range of validity (Glaser & Laudel, 2013). The academic researcher demonstrated this validity and reliability by setting aside preconceived biases, opinions, beliefs and prejudices about the subject matter to clearly understand the concept, perceptions and perspectives of the phenomenon of interest from the standpoint of those closest to those individuals experiencing the phenomenon.

This phenomenological study followed a four-step process that involved bracketing, intuiting, analyzing and describing (Van Manen, 1990):

1. Bracketing: A process of demonstrating the validity of data collection and analysis. It involved shutting off every bias, preconceived beliefs and opinions that one may have

about the phenomenon being researched to view the data in a pure form as much as possible.

2. Intuition: Requires the researcher to be engaged in the study and the phenomenon and remain open to the meaning attributed to the phenomenon as expressed by those who have experienced it or those closest to the individuals who experienced it.
3. Analyzing: Arranging findings by processes such as coding, categorizing and making sense of the essential meanings of the phenomenon to extrapolate themes and topics to draw out key issues being expressed by participants. In carrying out this step, the academic researcher had to be cognizant of personal prejudices and/or biases.
4. Describing: Understanding and defining the phenomenon to be able to communicate and provide unique descriptions. The main goal was to describe rather than explain the phenomenon.

The entire research process lasted about three months. The researcher interviewed 10 staff members (study participants) across all disciplines. These staff members were identified by the organization as those capable of providing valuable information regarding their homeless clients living with HIV/AIDS, their attitudes, practices, behaviors, perceptions and experiences with HIV, homelessness and ART adherence. The approach of interviewing staff members was relevant in ensuring input from those with far reaching experiences working closely with the youth experiencing the phenomenon (Collins, Onwuegbuzie, & Jiao, 2007).

Sample

This research project targeted homeless youth with confirmed cases of HIV living in California. Therefore, the population of this research study consisted of homeless HIV-infected youth represented by dedicated staff members (participants) who work closely with the youth in

various capacities providing life sustaining services to them such as accommodation, needs assessment, counseling, linkage to care (testing, diagnosis, insurance, medical, dental, medication), transportation, support, food, education, and many more. It is also important to note that the youth populations represented in this research were self-supporting youth, who lived apart from their parents and obtained help from government or private agencies. Few of them were either married and/or were parents. These youth clients made their own medical decisions, and therefore functioned as adults in the society.

Approximately 10 participants were selected for an in-depth face-to-face semi structured interview. The participants were selected from various disciplines; medical assistants, mental health therapists, housing supervisors, clinical supervisors, pre-exposure navigators, youth coordinators, managers and HIV blood testers. The 10 participants were selected on the following premises:

1. Demographics: The participants in this research were residents of the state of California, between ages 18 to 60, staff members who worked closely with homeless, HIV-infected youth, and have worked in the profession for a minimum of one year and could speak on their behalf and share their clients lived experiences.
2. Inclusion criteria: The study populations represented were resident of the state of California.
3. Exclusion criteria: Study participants who lived outside the state of California and participants who were non-staff members of the selected service organization used for this study.

Though the sample size appeared small, the decision to recruit 10 participants for this phenomenological research project was consistent with the sample size recommended for a

phenomenological project. According to Van Manen (1990), small samples (probably no more than 10 participants) are most suitable for a phenomenological research whereas Boyd (2001) regards two to 10 participants as sufficient to reach saturation in a phenomenological research.

Instrumentation

The survey tool used in this research was obtained from the Center for AIDS Prevention Studies (CAPS) and was modified to illicit responses from professionals who work directly with the homeless HIV-infected youth and can speak to their lived experiences with the intention of collecting accurate data for this research project. The permission to modify and use the CAPS survey instruments was granted by Daryl Mangosing, CAPS Research Communications Specialist, University of California-San Francisco, Prevention Research Center.

The CAPS is one of the world's largest research centers dedicated to social, behavioral, and policy science approaches to HIV. The mission of the CAPS is to end the HIV epidemic and associated health and social disparities by conducting high impact HIV prevention science and building capacity among researchers and communities to effectively address HIV.

Data Collection

Selecting the most appropriate data collection instruments was essential to the quality of the overall research study. This research project employed the use of qualitative methodology, using a descriptive phenomenological approach. Data was collected via semi structured interviews from two youth coordinators, a program manager, a mental health therapist, a medical assistant, an enrolment specialist, a housing/clinical supervisor, a prevention specialist, a prevention supervisor/pre-exposure prevention navigator and a HIV blood tester. The interview questions (see Appendix B) were formulated and geared towards their clients understanding regarding prevention and spread of HIV as well as adherence to HIV medications.

The academic researcher conducted one-on-one, face-to-face in-depth personal interviews with staff members of the organization responsible for providing services to these HIV/AIDS clients, the interviews lasted 1–1.5 hours. The interview form of inquiry provided valuable information and contributed to the overall knowledge of the public health issue drawn from the interviewees' responses representing their clients' perceptions and understanding of the phenomenon (Guion, Diehl, & McDonald, 2011).

The academic researcher obtained consent to interview and to audiotape the responses of ten selected staff from the specific service organization used in this research. The researcher also assured confidentiality of information to the staff members, and requested candid responses to all questions asked to be able to draw accurate conclusions capable of developing strategies for addressing the study conclusions.

After data was collected from all the participants, the audiotaped interviews were later transcribed verbatim by the academic researcher making sure to avoid any identifying information so that participants remained anonymous, unconnected and unidentifiable to their responses. The data was then organized into easily readable concepts and themes with the aim of identifying meaningful information and categorizing them. The themes emerging from the interview responses were used to create categories and subcategories for the coding framework and the identified themes represented the issues that were common between the members of the population being represented. The data obtained was then used to identify trends in the issue of nonadherence to HIV medications among homeless HIV-infected youth with intent of formulating interventional strategies capable of engaging the youth early in their infection to help sustain their treatment.

Data Analysis

The types of data analyzed consisted of qualitative data, based on field notes and audiotapes comprising answers provided by the staff participants during the interview sessions. The research was carried out using qualitative phenomenological research method with the goal of accurately describing the essential meaning of the homeless youth lived experiences in relation to their HIV management and medication adherence.

Phenomenological approach was used in analyzing each participant's transcript. This method involved all written transcripts to be read several times to identify significant statements and capture the themes/issues that were common between several participants as expressed in their client's experiences. Ten interview transcripts were imported into NVivo 11 qualitative data analysis software program that categorizes duplicate themes and supports the coding of written transcripts. Each line was manually read and coded into 12 major categories and several subcategories. Once the concepts and themes were coded, it was possible to find explanations for the results. The tables below were based upon qualitative coding from multiple open-ended questions as data were selected from within the tables to produce supporting charts.

In keeping with the methodology of qualitative research, the researcher collated and analyzed data from the 10 interviews. In looking at this qualitative research, the following questions were considered:

1. What patterns and common themes were mentioned in the interviews?
2. Did these patterns help to identify any issues?
3. Were there any deviations from the patterns?
4. Were there any patterns that suggested that additional data may need to be collected?

Analysis of these qualitative data required systematic data review, data coding, data categorization and data comparison to capture concepts and themes (O'Connor & Gibson, 2003). In capturing these concepts and themes, the researcher carefully focused attention to words or phrases that were frequently used throughout the interview dialogue as this allowed for information to be coded into categories as can be seen in the tables below.

The academic researcher ensured validity and reliability in the analysis process by devising a systematic approach for reviewing and evaluating data (O'Connor & Gibson, 2003). Data was validated using triangulation, which is done by ascertaining various perspectives from several independent sources (i.e., participants selected from several disciplines). In this research study, the 10 participants interviewed were selected from several varying disciplines.

The final stage of the data analysis required an interpretation of the data. In this final stage, the researcher utilized analyzed data to make statements that are representative of the population being studied as obtained from the representing participants interviewed. The final stage was to evaluate the data and provide answers to the research questions for a conclusion.

Ethical Considerations

The ethical issues of this research project were paramount due to the vulnerability of the research population. Vulnerability is important in HIV-related research because those infected with HIV may be medically vulnerable because of their infection; therefore, researchers conducting HIV-related research must pay attention to vulnerability and take steps to protect potentially vulnerable research populations.

Additionally, other ethical issues concerning the youth population revolve around informed consent, confidentiality, stigma, discrimination and protection of vulnerable groups. To that end, all the research participants were fully informed about the entire details of the research

project and were assured of the confidentiality in the discussions during the interviews. The research participants were required to give their consent before participating. Ethical standards also required that the academic researcher guarantee participant's confidentiality by assuring that identifying information was not to be made available to anyone who was not directly involved in the study. All the steps used in this research abided by the rules of ethical principles and the principles of voluntary participation prevailed throughout the research process.

CHAPTER 4. RESULTS

This chapter provided analysis and interpretation of the data collected solely from 10 face-to-face in-depth research interviews. The chapter presented a demographic overview of the studied population gathered from the interviews. Research questions were revisited, demographics were presented, and tables were established as part of the descriptive analysis of the study population. A detailed analytic summary of findings from the data as they relate to the research questions were also provided.

Interview Results

From 10 verbatim interview transcripts, the researcher performed an analysis using NVivo 11 software. The task revealed how raw data analysis from the 10 interview transcripts moved towards the recognition of overarching themes that encapsulated the phenomenon of the lived experiences of homeless youth in relation to their HIV management and ART adherence. In utilizing the interview questions, the core characteristics of the studied population as reported by the participants in the study (staff members of the selected service organization) were fully described in detail. The tables below detailed the frequencies and percentages of thematic statements and essential themes.

Table 1 displays the basic demographic characteristics of the clients being studied as it relates to sexual orientation, age, education level, ethnic group, primary language, employment status, marital status, other support systems and relationships. The age distributions of the clients were wide ranged; the clients primarily identified themselves as either bisexual, heterosexuals,

homosexuals or transgendered. They fell within the ethnic groups of African Americans, Biracial, Whites, Filipinos, Hispanics and Latinos. Their primary languages included Spanish, English and various Asian languages. In terms of marital status, the clients were classified as married, single or same sex couples. Regarding employment status, some were either fully employed, worked part-time, were paid volunteers or were fully dependent on governmental aid or disability programs. Their support system included family, friends and other support groups other than the service organization selected for this research study.

Table 1. *Client Demographics*

Demographic variable	*f*	%
Clients identify themselves as		
Bisexual	9	90
Heterosexual	3	30
Homosexual	10	100
Transgender	2	20
Average age range of clients		
30 or younger	6	60
Wide range	4	40
Highest level of education		
College or some college	8	80
From country of origin	1	10
GED or less than 12th grade	3	30
High school diploma	4	40
Ethnic group		
African American	9	90
Biracial	1	10
White	3	30
Filipino	1	10
Hispanic/Latino	8	80

Primary language		
Asian	1	10
English	10	100
Spanish	2	20

Table 1. *Client Demographics* (*continued*)

Demographic variable	*n*	%
Employment status		
Employed	3	30
Government aid or disability	3	30
Part-time or paid volunteer	1	10
Unemployed	5	50
Relationship status		
Married	2	20
Same sex	4	40
Single	9	90
Married or have kids		
None	4	40
Yes	6	60
Other support systems		
Family	4	40
Friends	2	20
Other service organizations	8	80

Table 2 illustrates in detail the residential status of the clients. The table also shows the percentage of those who are homeless, where they live and how long they reside in one place before moving on to another.

Table 3 outlines the attitudes of the clients towards living with HIV/AIDS, whether they freely discuss their HIV status and if yes, with whom? The table also highlights clients' attitude towards HIV disease, particularly whether they consider the disease a serious public health problem in the county where this research study was conducted. The table also outlines the clients understanding and knowledge about the disease and its transmission. It explores how long they have been living with HIV, their experience living with the disease and how the disease

influenced their lives. The table also outlines how the diagnosis changed and/or influenced their lifestyle and what gave them hope to overcome the challenges posed by the disease.

Table 2. *Accommodation (Residential Status) of Clients Represented*

Accommodation (residential status)	*f*	%
Percentage homeless		
0–25%	1	10
26–50%	1	10
51–75%	5	50
76–100%	3	30
Where they live		
Cars	1	10
Do not know	2	20
Friends/couch surf	6	60
Garage	1	10
Hang around the service organization	1	10
Hotels	1	10
Housing placements	3	30
Parks	1	10
Shelters	7	70
Streets	5	50
Warehouses	1	10
How long they live in one place		
Days	3	30
Do not know	2	20
Months	5	50
Weeks	3	30
Years	1	10

Table 3. *Clients' Attitudes to "Living with HIV/AIDS"*

Attitude	*f*	%
Attitude living HIV/AIDS		
Depressed, apathetic, negative	6	60
Optimistic, positive	7	70
Freely discuss status		
No	9	90
Not sure	1	10
Yes	7	70
If yes, who with		
Advocacy events	2	20
Staff of Service Organization	3	30
Family	3	30
Friends	3	30
Partners	1	10
Technology	1	10
Consider serious problem in California		
No	7	70
Yes	3	30
Understanding of HIV		
Outreach, educate	3	30
Personal opportunity	3	30
Prognosis	2	20
Self-care	2	20
Stigma	2	20
Symptoms, side effects	2	20
Transmission	3	30
Treatment	4	40
Knowledge HIV transmission		
Informed	10	100
Uninformed	4	40
Years living with HIV		
0–10 years	6	60
10+ years	5	50
Unsure	1	10

Table 3. *Clients' Attitudes to "Living with HIV/AIDS"* (*continued*)

Attitude	*f*	%
Their experience HIV		
Negative, in transmission	8	80
Positive, adjusting	6	60
HIV influenced their lives		
Negative impact	6	60
No influence	1	10
Positive impact	8	80
Diagnosis changed lifestyle		
Negative	6	60
No change	4	40
Positive	7	70
Gives them hope		
Support of the service organization	9	90
HIV community	2	20
LGBT mainstream community	1	10
Other agencies	1	10
Spiritual faith	1	10
Treatment advances	1	10

Table 4 evaluates the client's medical history specifically as it relates to behavioral health. It covers areas such as mental health, sexual abuse, drugs and alcohol involvement, and other factors responsible for the client's failure to adhere to HIV treatment regimen.

Table 4. *Medical History (Behavioral Health) of Clients Represented*

Medical history (behavioral health)	*f*	%
Major issues hinder	7	70
Factors in failure to adhere ART		
Alcohol	9	90
Mental illness	10	100
Sexual abuse	7	70
Yes	4	40
No	3	30
Substance abuse	1	10
Other issues failure to adhere ART		
Financial	3	30
Forget or lose pill bottle	2	20
Homelessness	2	20
Housing	1	10
Sex addiction	1	10
Side effects	1	10
Stigma	4	40
Lack of support	2	20
Unstable lifestyle	1	10
Drugs or alcohol prevent meds	10	100

Table 5 identifies several reasons offered by the youth as to why they miss appointments, as well as the common reasons for their poor adherence to ART regimen.

Table 5. *Clients' Adherence to Medications/Accessibility to Clinic*

Adherence/accessibility to clinic	*f*	%
Length of ART treatment		
Consistent	5	50
Inconsistent	6	60
Take traditional meds with ART		
Do not know	9	90
Natural holistic supplements	1	10
No	3	30
Prescribed other	3	30
Why not adhere to ART		
Financial	3	30
Mental/emotional	8	80
Physical	6	60
Stigma	5	50
System	1	10
Transient lifestyle	8	80
Why missed appointments		
Financial	3	30
Incarcerated	1	10
Mental	10	100
Physical	3	30
Transient lifestyle	6	60
Transportation	4	40
Form of transportation	10	100
Any factors affecting adherence ART	10	100

Table 6 illustrates the client's experiences in taking ARTs. It delves into factors that led the clients to start taking ARTs, how ART has changed their lives and how they think these medications work in their bodies.

Table 6. *Experience with Taking ARTs of Clients Represented*

Experience taking ARTs	*f*	%
What led clients to start taking ARTs		
Education, social outreach	7	70
Housing	2	20
Testing, diagnosis, treatment	7	70
How ART changed lives		
Negative	4	40
Positive	10	100
How they think ARTs work in body	10	100

Table 7 depicts various types of stigma perceived by the clients. In addition, the table highlights reported experiences of bias and discrimination suffered by the youth because of their positive HIV/AIDS status.

Table 7. *Perceived Stigma Demographics of Clients Represented*

Perceived stigma	*f*	%
Perceived stigma		
Fear of rejection	6	60
Labels	5	50
Medications	5	50
Organization's name	3	30
Shame	3	30

Table 7. *Perceived Stigma Demographics of Clients Represented* (*continued*)

Perceived stigma	*f*	%
Treated differently due to HIV-positive		
Beaten up	1	10
Denied services	1	10
Institutional (Institution's name)	2	20
Judged	3	30
Shunned, avoided	6	60

Table 8 brings to limelight the many reasons why Homeless HIV youth fail to adhere to HIV treatment regimen.

Table 8. *Perceived Self-Efficacy to Adhere to ARTs of Clients Represented*

Perceived self-efficacy to adhere	*f*	%
Fear of exposure	3	30
Food issues	3	30
Forget	4	40
Hate taking medications	2	20
High on drugs	4	40
Pills not on them	5	50
Sick	1	10
Side effects	2	20
Transient lifestyle	3	30
Want a break	1	10

Table 9 clearly shows strategies that have been tried by the clients as well as strategies that have been used by staff to encourage the clients as a way of reminding them to take their HIV medications.

Table 9. *Strategies Applied for Taking Medications*

Strategies applied for taking medications	*f*	%
Alarms	5	50
Behavior charts with rewards	1	10
Family member supervises	1	10
Phone applications	1	10
Pill boxes by day of week	1	10
Routine time of day	5	50
Set goals	2	20

Table 10 displays most of the reported side effects that the clients have reported or discussed.

Table 10. *Clients' Perceived Side Effects of ARTs*

Perceived side effects ARTs	*f*	%
Aches (muscles and joints)	1	10
Dizziness	2	20
Fatigue	2	20
Feel sick in general	3	30
Gastrointestinal discomfort	7	70
Insomnia	2	20
Nightmares	3	30
Taste	1	10

Table 11 conveys the extent of patient–provider communication reported by the provider and highlights how helpful the identified service organization has been to the HIV infected youth since they became clients of that service organization. The table also identifies the level of governmental involvement in helping the clients adhere to antiretroviral therapies.

Table 11. *Patient–Provider Communication Statistics*

Patient–provider relationship	*f*	%
Patient–provider communication		
Empathetic	2	20
Financial support	2	20
Mentor–mentee	2	20
Open, nonjudgmental	6	60
Overall good	2	20
Professional advice	2	20
How helpful the service org. since diagnosis	10	100
Role of govt. agencies with adhere to ART		
Do not know	1	10
Good programs	5	50
Should do more	5	50
Anything else the organization can do		
No	2	20
Yes	8	80

Table 12 reveals a vast array of services rendered by service organization to homeless youth living with HIV/AIDS.

Table 12. *Services Rendered to Clients by a Selected Service Organization*

Services	*f*	%
Accommodations	6	60
Adherence reminders	7	70
Counseling	9	90
Dental care	4	40
Education	10	100
Food	5	50
Gift cards	3	30
Incentives	7	70
Insurance	5	50
Medical care	9	90
Medications	10	100
Needs assessment	3	30
Outreach	4	40
Support groups	7	70
Surveys	1	10
Testing and diagnosis	8	80
Transportation	4	40

Significant Statements, Emergent Themes, and Interpretations

Theme identification is the heart of data analysis. It is an act of searching for themes that surface as being prominent to the description of the phenomenon (Daly, Kellehear, & Gliksman, 1997). The process involved pattern identification within the data being analyzed and required singling out of themes or phrases through several "careful reading and re-reading of the data" (Rice & Ezzy, 1999, p. 188) for analysis. In this method, the 10 verbatim interview transcripts were read severally to extrapolate themes, phrases and statements that pertained to the lived experiences of homeless youth in relation to their HIV management and medication adherence. The approach was then used to complement the research questions, allowing the use of phenomenological approach. The approach enhanced the research questions permitting the concept of phenomenology to be fundamental to the process of deductive analysis in allowing themes to surface straight from the data collected using the coding process.

This section also discussed the results of data analysis from the data collected through interviews. Data was assessed using the NVivo 11 software for a sample of 10 staff participants representative of a population of homeless HIV youth served by a selected service organization. The results of the data analysis are presented below to attempt to provide answers to the following research questions:

1. What are the perceptions of HIV-infected youth experiencing homelessness regarding adherence to HIV medications or any other HIV treatment regimen?
2. Excluding homelessness, what other lived experiences/factors of the homeless HIV-infected youth are responsible for poor adherence to HIV medications or any other HIV treatment regimen?

3. Are there differences in the rate of adherence to HIV medications or any other HIV treatment regimen between the lived experiences of homeless HIV youth and their counterparts in the general population?

The researcher asked several interview questions that covered the perceptions of HIV-infected youth experiencing homelessness as well as the issues of nonadherence. Below were the responses to the interview questions and the themes that emerged. These identified themes represented the issues that were common between the members of the population being represented.

Research Question 1

Perceptions of homeless HIV youth regarding medication adherence. Two dominant themes emerged when the respondents were questioned on the perception of the youth regarding medication adherence: negative perceptions and positive perceptions.

Negative perceptions. Three of the respondents believed that the homeless youth have negative perception regarding medication adherence. According to some of the respondents, some of the youth miss the medications because they do not want other people to know that they are on HIV medications. Respondent 1 stated, "The fact that they have to take meds. They don't like to take medication. They have to—the fact that they have to hide it. So—because they don't want anyone to find out that they're HIV-positive."

In some occasions, for reasons best known to the youth they skip their medications and lie to their doctors and caregivers about it. Some other respondents believed that the physicians were also partly to blame for the failure of the youth to maintain maximum adherence. This is because in some occasions, the physicians failed in their responsibilities to fully explain the

importance of adherence, side effects and how the HIV medications are different from other medications. Respondent 3 stated,

> "And a lot of 'em I think aren't told that once they do get their pills. It's like okay; we checked your blood count and your T cells and all that. And this is the medication you're going to take. You know, the doctor doesn't really say okay, if it's not working or you're feeling sick after a week, you know, a week to two weeks, your body should get used to it and you should be fine. If not, you know, come back in. We'll try it again. Give you another medication. Thinking that's the bad part that they don't know."

Positive perceptions. On the flip side, many of the respondents reported positive perceptions of medication adherence by the youth. Seven out of the 10 respondents reported that their homeless HIV youth clients associated medication adherence with longer and healthier life, more energy, undetectable viral load, higher T-cell count, and the ability to obtain housing. According to Respondent 4, majority of the clients who come to them maintain strict adherence to their medication because "it extends their life expectation." Similarly, per Respondent 8, these youth clients are encouraged to adhere strictly to their medications because,

> "They're living a lot longer and healthier lives. . .. cause when they came in, they were at this level and because of the medication, you know, they're at this level. You know, their undetectable viral load and higher T cell count and stuff."

Two other respondents mentioned that once the youth can survive the initial problems associated with side effects they come to appreciate why they should not skip their medications. Respondent 6 stated,

> "They feel more—they feel more in tune with the virus, and they feel like they are doing their part to stay healthy. So, they're on medication and they realize that the side effects are not there, that it's just like taking a daily vitamin. They feel more empowered and then they feel more in control of the virus."

The reaction and acceptance of the importance of adherence by the homeless HIV youth underscores how important it is for physicians and care providers to adequately prepare the youth

to make sure that they fully understand the benefits and side effects of HIV medications before they commence treatments.

Problems associated with poor adherence. Respondent 8 stated,

> "From when I ask clients as part of the initial assessment is what would happen—what do you know about what would happen to you if you stop taking your medication? And it's—I've gotten pretty consistent answers for the most part. I want to say like 95% understand and know that their viral loads are what the medication is helping with, their T cell counts is what it's helping with. And that if they stop the medication if they're undetectable that the likelihood of them becoming detectable again is far greater."

All the respondents (staff of the service organization selected for this study) stated that majority of the youth are fully aware of all the problems associated with poor adherence to ART regimen. According to respondents, the poor adherence by the youth is not because of their lack of awareness of the dangers posed by HIV and the problems associated with poor adherence. According to Respondent 1, the youth are fully aware of the dangers posed by poor adherence:

> "I think they live in reality and they know if they stop taking it, and some of them had the experience, that their viral load escalates, their T cell count may drop, some infections that they have may come back or they may start to get infections, some of the infections that can happen."

Majority of the respondent's state that the youth know that adherence to ART medications are essential for longer, healthier lives. They also realize that failure to stick to their prescriptions will cause their HIV conditions to get worse as they are bound to get sicker, develop other health conditions owing from an increased viral load due to nonadherence or poor adherence. According to Respondent 4, "They know if they don't take it or if they stop taking it at some point, you'll get sicker and it can get worse, you know, so yeah."

Among the homeless HIV youth who are also clients of the service organization, the importance of strict adherence to medications is stressed as often as it is necessary. In addition, the youth are made to understand the consequences of nonadherence. Respondent 3 stated,

> "So, they know that they have to take it every day. And they do know that from the moment that they stop taking it, their viral load will increase. And therefore, they will have other medical conditions. So, they are aware of that because we—every time they will have any contact with us, we will say something. If they see the doctor, the doctor reminds them about the consequences of not taking their meds. So, they know."

Barriers to adherence encountered by homeless youth. The respondents identified several factors that make it difficult for homeless youth to strictly adhere to their ART medications. Some of these factors as identified by the respondents include intentional forgetfulness, fear of disclosure of their HIV status to their family and friends, the complicated nature of the ART regimen, lack of readiness on the part of the youth, and lack of consistency regarding time to take the medication.

Forgetfulness. The respondents identified two different forms of forgetfulness that are barriers to the youth maintaining faithful adherence to their HIV medications. This forgetfulness could sometimes be intentional forgetfulness and could sometimes be unintentional due mainly because of the homeless status of the youth, their busy schedule or lifestyle. Respondent 7 stated,

> "So, I think they're just intentionally not carrying the medications with them, so they forget about them. . .. A lot of them won't keep them in pill bottles. They'll just keep them in baggies because they're hanging out with people. They don't want them to know that they're HIV meds."

Respondent 4 stated, "Most of them just forget. They just say their lives are so busy, they forget. And we try to put them on a routine and get a routine started with them."

Fear of disclosure/hiding their HIV medications and status from family and friends. Many the youth keep their HIV status secret. To maintain this secrecy, they try to hide their medications away from their families and friends. The result is that on some occasions, these youth clients will skip their medications to avoid exposing the fact that they are on HIV medications. Respondent 5 stated,

> "A lot of them won't keep their medication in pill bottles. They'll just keep them in baggies because they're hanging out with people. They don't want them to know that they're HIV meds. But living at home even for some people because their families don't know, and they still have to hide their pills at their friend's house or—the friend who knows that they're positive, so they have to go there and take it."

Food issues. The ART regimen demands strict adherence. Most often, patients are required to take their food and medications at the same time (all the time). According to some of the respondents, the fact that these medications demands that youth take it with food, often present serious challenge as the homeless youth may not have food readily available. Respondent 10 stated, "Not being able to eat at the same time all the time. Some days may be different. They might not be able to eat until the end of the day." Respondent 2 stated, "Some are taking their medications with food actually, and they—they report food. The don't have food and so . . . so could not take the meds."

Side effects. The ART regimen comes with several side effects. These side effects make it difficult for some of the youth to ever get accustomed to the medications. Some of the youth openly admit that they hate taking the medication because of how these medications make them feel. Respondent 1 stated,

> "They just say plain that they don't want to take it because they hate it. You know, sometimes they'll rip up their pills before they leave here, like when they get them from next door so that people can't see that. . .. Sometimes they feel so sick to take pills that they just wanted not to."

High on drugs. The respondents reported that drug and alcohol addiction are some of the major reasons why the youth fail to adhere to their HIV medications. According to the respondents, when these youth clients are high on drugs, adhering to their ART regimens is the least of their worries. Respondent 3 stated, "Typically when they're high, what'll happen is

they'll be like I can't remember my meds and I'm high! You know, like they'll say that the times when they do use drugs."

Transient lifestyle/pills not on them. A good number of the homeless youth live a transient lifestyle thus they are constantly moving from one location to another. For these youth, it is often difficult for them to carry their medications with them all the time. Respondent 6 stated,

> "Keeping them on them because a lot of them go from one place to another place. So, the challenge is having them keep their medications on them. Because a lot of them won't keep them in pill bottles. They'll just keep them in baggies because they're hanging out with people. They don't want them to know that they're HIV meds."

Facilitators to adherence among the homeless youth. These are basically strategies used by clients to remember to take their medications. Patients employ different strategies to help them improve on their adherence to their ART medications. Some of the strategies used by the homeless youth (revealed by the respondents) include use of alarms, use of behavior charts with rewards, phone applications, pill boxes by day of week, routine time of day, and many more.

Alarms. Four of the respondents noted that the youth use clocks or cell phone alarms to help them remember to take their medications. Respondent 7 stated,

> "No. I just—I think the alarm thing works pretty good for them because I've had quite a few say hey, my alarm goes off at this time or they set it to be able to take it the same time every day."

Respondent 1 stated, "Some of them have shared that they do use the alarm on their phone."

Behavior charts with rewards. Some clients use a reward system (where they reward themselves for faithfully adhering to their medications). To track their adherence, these clients keep a behavior chart. The respondents reported that the service organization had worked with

several clients helping them set up reward systems and often giving them gift cards. Respondent 8 stated, "Yeah, I've actually worked with some clients to set up behavioral charts. And for them to stay on it, they give themselves a reward at the end of that week."

Family member supervises. The respondents reported that some of the clients have improved on their adherence to their HIV medications because of the involvement of family members and friends supervising their adherence. Respondent 6 stated,

> "But now his auntie is a bit more involved and she picks up the medication, she gives him just one. She watches him take it, and then it just goes from there. So, he's doing other things to get the drugs, but the medication part's taken care of . . . there's a few like my client who was selling medication, now his auntie is watching him."

Other strategies reported by the respondents that are used by the youth to monitor and improve medication adherence include the use of reminder devices like phone applications, use of pill boxes that show days of the week, building their medications into their daily routine/schedule and setting personal goals for themselves. For example, some patients have set life goals. These goals include furthering their education or getting married. They realize that adhering to their ART medications will help them achieve their set goals.

At the service organization where this study was conducted, case managers check on their youth clients from time to time to make sure that they maintain adherence to their ART medications. Respondent 2 stated,

> "So, I will challenge them, you know, hey, you mentioned that you—that you want to take your medication daily, you know, so this week, let's try you taking it daily, you know, and see how it happens. And they'll come back in to report, you know, I did five days. Well, that's better than last week. You know, you went three days last week so let's keep trying that."

Research Question 2

Factors besides homelessness responsible for poor adherence. Homelessness is the major barrier to medication adherence by the homeless youth living with HIV/AIDS. However, it is not the only barrier. The respondents (service organization staff) discussed other barriers reported by their clients (the homeless youth), which are contributory to their failure to strictly adhere to their HIV medications. Some of these identified barriers include the societal stigma attached to HIV/AIDS, the fear of being labeled as a slut or gay for being HIV-positive, the side effects associated with HIV medications and many more.

Perceived stigma. The respondents reported that several of the youth failed to adhere to the strict ART regimens because of the societal stigma attached to HIV. Sometimes; they keep their HIV medications away from friends and families for fear of being rejected once they discover that they are living with HIV. Respondent 5 stated, "There are some institutional stigmatization that goes on with them that they've shared about a little bit. Yeah… People not wanting to date them if they openly disclose their status . . . so that is something that really plays a huge part."

Fear of being labeled. Some of the youth dread being called "whores," "sluts," "queers," or "gays" because of their HIV status. The fear of labels and rejections often deter these HIV-positive individuals from bringing out their medications to avoid people knowing that they are living with HIV. Respondent 3 stated, "Just they feel like . . . if someone finds their pill bottles that they're just going to be labeled as a whore or, you know, that they're dirty or they're sleeping around. Like that's still, you know, in their head."

Other barriers to HIV medication adherence reported by homeless youth via the respondents include doubt on the youth side regarding the efficacy of the medication, the belief by some of the youth that the medications make them sicker.

Stigma and discrimination suffered by youth living with HIV. The respondents reported that some of the youth have reported suffering different forms of discrimination and harassment because of their HIV status. According to the respondents, some of the youth reported being beaten up, denied services and often discriminated against. Respondent 3 stated, "Mm hmm. Some of them have gotten beaten up for being positive." Respondent 6 stated, "You know, just denied services. People, you know, just treat 'em wrong."

The respondents also mentioned that some of the youth suffer unnecessary humiliations and are called names by people who believe that their HIV status is a result of their promiscuous life style. Respondent 9 stated,

> "But I think I've had many, many clients be accused of being sluts, being dirty, being almost asking for it because they've, you know, engaged in whatever behaviors they have. And it's like they get the response well, like what did you expect? And there's no real empathy or even sympathy for those clients. And so, I think there's a lot of the accusation of being dirty, being promiscuous, being damaged goods."

Perceived side effects. The ART taken by most youth living with HIV involves them taking two or more drugs each day for the rest of their lives. These Antiretroviral drugs can cause severe side effects. These side effects have often been cited by youth living with HIV as the reasons for poor adherence. According to the youth, some of the side effects associated with antiretroviral medications include dizziness, muscles aches, joint pain, fatigue, feeling of sickness, insomnia, nightmares and gastrointestinal discomforts such as nausea, vomiting and diarrhea. Respondent 2 stated, "Yeah. Some, they hate the feeling that they get side effects...

Others are like what the hell is this? I don't know what's going on! . . . You know, and if it's ongoing for like a month," Respondent 10 stated,

> "Yeah. There's—I mean just because HIV medication, you know, it is a really demanding drug. . .. You know, and it doesn't help that I don't have food in my stomach because a lot of those pills you need to take food with. So why am I going to take—I'm already feeling sick as it is because I have no food in my system. Why am I going to take this pill to get me even more sick because it's just—the pill is just in my stomach."

Research Question 3

Differences in HIV medication adherence, homeless youth versus general population. ***Depressed, apathetic, negative.*** The attitude of most youth changes as soon as they are diagnosed with HIV/AIDS. Interviews with the service organization staff members suggest that irrespective of homelessness, the attitude of every youth changes. These changes are manifested by shock, depression, anxiety, shame, and guilt. For homeless youth, HIV diagnosis complicates their existing perilous conditions. Some of the respondents reported that at the onset of their diagnosis, many of the youth express that they do not really care whether they live or die. According to Respondent 8, HIV diagnosis is followed by a lot of depression. "I get a lot of clients with depression. A lot of clients with sex addiction. I get a lot of clients who present with symptoms of anxiety and substance abuse."

According to the service organization staff, all youth, whether they are homeless or from the general population they have the same reaction when they find out that they are HIV-positive. Respondent 4 stated, "There's a lot of shame, a lot of guilt. I think those two things are pretty heavy when there's a new diagnosis, the shame and the guilt, that I did something to deserve this."

Optimistic, positive. The respondents reported that with the advent in medicine, most of the youth no longer feel that a HIV diagnosis is a death sentence. According to Respondent 7,

> "Some of them are open about it and have a good attitude because I let them know that HIV and HIV-positive is no longer a death sentence. You can live a long, healthy life as long as you're adhering to your medication and you're doing everything that you need to do."

According to the respondents, many of the homeless youth feel happy once they are diagnosed with HIV. This is because being HIV-positive not only helps them to get accommodation; it also ensures that they qualify for additional benefits.

Attitude towards HIV. Several of the participants that were interviewed were emphatic that the youth do not consider HIV/AIDS a serious problem in the county where this research study was carried out. The youth considered substance abuse and homelessness as greater challenges to public health than HIV. When asked whether their clients considered HIV as a serious public health problem in that county. Respondent 1 stated,

> "No. They consider probably drugs and alcohol more serious than HIV. For them, living on the streets is just day to day, you know, trying to survive and trying to get money to eat pretty much. They're not even worried about HIV or it developing into AIDS or anything like that. That's really the last thing on their mind."

Respondent 9 stated, "And it's sad to say that a lot of times, I will have clients tell me that they're trying to catch HIV, so they can get services offered to them."

The respondents reported the disappointment of some of the homeless youth who are HIV-negative. Respondent 5 stated, "So if I go out and get HIV, you guys can give me a house to stay, you know." Respondent 4 stated, "Nope. They know they can benefit from being HIV-positive. They know [laughs] they can get housing and food and stuff because they have it. Some of them even try to get HIV just for the housing."

Youth understandings of HIV. The respondents offered mixed messages about the youth understanding of the seriousness or dangers posed by HIV. While some respondents reported that the youth have very limited understanding of the dangers posed by HIV to the

youth and the society in general, other respondents reported that not only do the youth know the dangers the disease poses; they also understand what they should and should not do when they test positive for HIV. Respondent 8 stated,

> "But yeah, I was like hmm. So, they know it's—they have a sense of it's an infection they have, and they have to take medicine for it. They've got to go to the doctor. They should not be having sex with people without a condom. They should be talking about it, but then the stigma jumps up. You know, if I talk about it, they're going to think I'm this way or that way."

In addition, the respondents reported that the youth know fully well the prognosis of the disease. Respondent 2 stated, "They know that it's manageable, it's treatable, but there's no cure. I think they know the psychoeducation part of it, of how it causes you to have certain symptoms, depression. Some days, you'll feel good. Some days, you won't."

Seventy percent of the respondents reported that even though the youth know the dangers posed by HIV, their actions and lifestyles do not show that they consider it very serious. Respondent 5 stated, "I feel like they don't take it as important as they should, but you just don't see that kind of like sense of urgency like when it comes to like taking care of themselves."

Personal opportunity. According to the respondents, while majority of youth realize that HIV is a serious health problem, some of the infected youth see their HIV status as an opportunity to get free accommodation and other benefits and help from the selected service organization used in this research study. According to Respondent 3, "They understand it. They know they can benefit from it. They know [laughs] they can get housing and food and stuff because they have it. Some of them even try to get HIV just for the housing."

In addition to the entitled benefits (housing, food vouchers and many more), the homeless youth receives when they are diagnosed with HIV/AIDS. Some of the youth especially those that have a history of substance abuse see their infection as an opportunity to make quick money to

sustain their addiction. Respondent 7 stated, “Some of them sell their pills, which is really playing with fire.”

Youth knowledge about HIV transmission. Majority of the respondents reported that most of the youth are well informed of how HIV is transmitted from one person to another. They reported the youth know that most of them get infected through needle sharing and through unprotected sex with multiple partners. Respondent 9 stated, “I think some of them are very well informed and could actually educate their partners about it and can educate other clients about it.” Respondent 2 stated, “They’re pretty knowledgeable about how it’s transmitted. Like they know that it’s not transmitted through saliva. We do weekly groups and then sometimes we call on them to teach those groups back. It’s just actions.”

According to the respondents, the toughest time for most of the youth was at the period when they were initially diagnosed with HIV. Respondent 10 stated,

> “It’s—it’s a wave, cause even though like they’ve had it for an average of three years, I feel like 50% didn’t adjust right away. And even now like when I give the diagnosis, not all of them are ready to like start medication right away. Not all of them are ready to just transition to that life. So, it’s a mix.”

But over time, the youth reported that they get used to the medications and the side effects associated with it. The youth also stated that over the years, “the medicines have definitely improved and progressed. They have said that at one point, they didn’t trust the meds, but now it’s a little easier to trust the meds” (Respondent 7). With the passage of time, the youth get more comfortable with their HIV medications. Respondent 4 stated, “Like I said, they’re a lot more comfortable. They’re more, you know—like they address the fact that they have this, they’re taking their medicines, they’re trying to live healthy on top of, you know, the medicines and everything.”

The impact of HIV on families. The diagnosis of HIV not only affects the youth, but also their families. HIV impacts the lives of the youth in various ways. According to the respondents, HIV diagnosis is known to have led to separations in families. Respondent 9 stated, "It definitely tore families apart for some of my clients." "On the flip side, the diagnosis of HIV is known to have made some positive impact on the lives of some of the youth especially the youth on the fast lane." According to the respondents, most of the youth diagnosed with HIV became more aware and more responsible with sexual relationships. Respondent 1 stated,

> "For the ones that know that they are HIV-positive, they know that they have to make life changes. Friends that they have to take care of, that they think they need to take their meds, they need to live—if they need mental help, they have to look for that, so some—they are like focused, but mainly on their meds."

Respondent 5 stated, "And there are others who feel compelled to attack it straight on and who dedicate themselves to understanding and making sure that they're healthy and however that looks like that for that person." Respondent 7 stated, "It has influenced them to seek treatment, to begin to take better care of themselves and their families."

Effects of HIV diagnosis on the lifestyle of the youth. ***Negative.*** For some youth, the diagnosis of HIV leads them to make negative life changing decisions, for many of them, once their HIV status is confirmed, they experience depression and engage in reckless behavior. Some of the youth I was told, go into self-exile to Palm Springs, a city that has a large lesbian, gay, bisexual, and transgender (LGBT) community. There were also several of them who get more reckless by indulging in the same risky activities that may have been responsible for their HIV status. Respondent 5 stated, "And then for some of them, they go into hiding and isolation. It has changed their life and it's in a, you know, you're depressed, you go into isolation." Respondent 1

stated, “Yes—if you’re positive with HIV and if you’re of a certain age, and you are male and gay you go to Palm Springs because that’s where people go to be exiled.” Respondent 9 stated,

> “But then there’s the other side of that hand where there are people who are like well, I’m HIV-positive so I can pretty much do whatever I want! I could have unprotected sex all I want because I already have HIV. And may not understand how the virus may work and—will go and continue to do high-risk—what we call high-risk behaviors.”

Positive. For some of the youth, the diagnosis of HIV has brought about some positive changes in their lives and lifestyle. According to some of the respondents, being diagnosed with HIV has become a wake-up call for some of them to make changes in their risky lifestyles. Respondent 1 stated, “Some of them, they change their lives and become—wanting to become healthier, more aware while others of them are now coming to be activists where they go into HIV prevention work.” Respondent 3 stated, “I would say most of our clients, about 75% have changed their behaviors. Maybe they’re either disclosing to their partners, they’re wearing condoms or—and taking back what we’re giving in the groups. They’re going back with that.”

The respondents reported that several of the youth changed their perspective, their way of thinking, the way they care for themselves and how they value their health and their life. Some of the lifestyle changes reported by the youth include changing their diets and getting involved in exercise; some of them get involved in meditations mindfulness. Some also become compliant with their doctors’ appointments and are more faithful in adhering to the HIV medications. In addition, some of them become more protective of their partners. Respondent 5 stated, “And now that we have PrEP [pre-exposure], for their partners is a way of keeping themselves negative. So, I think they—I think they’re more educated.”

What gives the youth hope to beat the HIV? The diagnosis of HIV is very tough on most of these youth clients. For some of them, life becomes meaningless the moment they are

confirmed HIV-positive. For some, things become so bad when everything else associated with the disease are considered—the stigma, the discrimination they suffer, the associated side effects of the medications, and the high rate of mortality and morbidity that goes with living with HIV.

With the advancement made in medicine and the treatment of HIV, the disease is no longer the death sentence that it used to be. Now, most people living with the disease including the homeless youth are very hopeful of beating the odds and living very healthy and happy lives. According to the respondents, several factors are responsible for the hope and optimism shared by some of these clients. Agencies like the service organization used in this research study (which provides not only housing but food and basic provisions to the youth) were cited as one of the major source of hope to the youth. Other sources of hope include the care and love they receive from the staff and their mentors at the service organization, the support they get from their friends and peers who serve as support network and meeting long time survivors of HIV.

Service organization support. Respondent 7 stated,

> "It gives them hope, the fact that they will find a place like us that will help them try to meet their basic—not their basic needs, but some of their needs. Like if we help them with housing, we help them with food, we help them with their medical insurance and getting the care that they need. So, they feel like okay, and also the fact that it's always a program that will help them to get their meds. So, it's all of that."

Support network. Respondent 1 stated,

> "They get hope from meeting other young men or other people who are long-term survivors. . .. So, when they see people who are long-term survivors who are living healthy and happy, it encourages them, and it makes them feel better about themselves."

HIV community. Respondent 2 stated,

> "Seeing other positive folks moving forward. I think what also gives them hope outside of the selected service organization and the other agencies that they may encounter is that, you know, the agencies—they see that the agency cares about them. And I think when they connect with or see that certain staff or there are some staff members at the

> agencies that also live with it and are doing pretty well, that they can gravitate to them, get a little hope from looking at those folks as well, you know."

LGBT mainstream community. Respondent 5 stated,

> "I think also the LGBT mainstream community. I think that gay establishments, restaurants, bars, agencies are more willing to promote HIV health whereas I think before it was stigmatized within the community and people weren't willing to associate their business with HIV because people might not like that I promote that."

Respondent 7 stated, "I think the conversations and agencies like these that normally do outreach, now we have agencies and organizations more willing to partner with us because there's less of a fear of being associated with HIV and AIDS."

Social/emotional barriers to medication adherence. The respondents identified depression, drug/substance abuse, homelessness, lack of education, mental health, side effects, the efficacy of the medication and the urge by some of the youth to sell their medication to fuel their drug use as some of the social/emotional barriers to medication adherence reported by the youth.

Selling HIV medications for substance abuse drugs or for food. Respondent 6 stated, "Because they want to sell their meds for money because they're homeless and they need money."

Depression. Respondent 3 stated,

> "Depression, drugs, homelessness. Some of them, you know, have to eat food with the medications and by them being homeless, it's hard for them to get food, you know, at the right time and eat the—you know, get the medicine. It has to be taken with the medicine for it, you know, to even have an effect."

Mental health. Respondent 1 stated, "Mental health problems and social issues is like financial issues."

Substance abuse. Respondent 4 stated, "Substance abuse, definitely. . .. Substance abuse, like I said, smoking and drinking. Sometimes they forget."

Social acceptance. Respondent 10 stated,

> "Social acceptance. Lack of family support. And it stems from just their sexual orientation. By them being gay, they already have been ostracized and alienated by family and community. . .. So just that lack of community support about what they're going through, it plays a major part in just how they deal with life."

Effects of the social/emotional factors. ***Substance abuse/alcohol.*** Majority of the respondents identified substance abuse as the most serious barrier to medication adherence as reported by the youth. The respondents reported that majority of the youth fail to adhere to their HIV medications most of the time because they are "too high" or because the medications have serious side effects when taken alongside other street drugs. Respondent 6 stated,

> "For our clients, I would say about 50% at least would be just from substance abuse and alcohol. A lot of 'em do live on the street so, you know, they forget their pill bottle, or they lose it or, you know, they're just—sometimes they just go on the streets and try to find food or, you know, companionship and they just—that—those pills or that one day of pills is not even on their mind, you know. If their stomach is growling, they're going to go find food. They're not going to take the pills, you know."

Mental illness. The respondents reported that mental health problems are another known barrier to HIV medication adherence by the youth. Respondent 8 stated, "Substance abuse and mental health issues. Mental health, untreated, they can probably tend to forget to take their medicine. But some of the guys that I have actually with the mental health issues are actually negative."

Sexual abuse. The respondents believed that only a small percentage of the population associate their failure to adhere to their ART medications to sexual abuse. It is also possible that the percentage of the youth traumatized by sexual abuse is more than the percentage reported;

this may be so because the issue of sexual abuse is such a sensitive issue which most times gets unreported by the victims. Respondent 4 stated,

> "Sexual abuse, I think—there's a small percentage. You know, it would be difficult for me to say. There are many clients who will not disclose—may allude to some abuse, but won't disclose it. There are other clients who are very upfront about past sexual trauma. But I would say—mmm—it would have to be at least from my experience less than 30% actively disclose, about 20%—anywhere from 20 to 30 will disclose that there's some sort of sexual trauma in their history."

Other issues that contribute to failure to adhere to HIV medications. The respondents identified other issues that are barriers to adherence by the homeless youth. These factors include lack of money, issues associated with homelessness, transportation and unstable lifestyles.

Money/transportation. Respondent 8 stated, "They have a hard time even coming here—but needed six bus tokens to come to his following appointment afterwards because he had three of them." Respondent 4 stated, "They'll sell their drugs, and then they'll buy their street drugs so yeah. So that plays a part in this."

Forget or lose pill bottle. Respondent 4 stated,

> "A lot of them do live on the street so, you know, they forget their pill bottle, or they lose it or, you know, they're just—sometimes they just go on the streets and try to find food or, you know, companionship and they just—that—those pills or that one day of pills is not even on their mind, you know. If their stomach is growling, they're going to go find food."

Homelessness. Respondent 7 stated,

> "I would say home—homelessness. Because if you're homeless and you're living on the streets, a lot of them don't like to sleep at night because in fear of their stuff getting stolen so they're going to stay up at night."

Side effects. Respondent 10 stated,

> "They'd just rather not deal with it because not only am I on the streets, you know, sometimes the medication is making me sick. You know, and it doesn't help that I don't

> have food in my stomach because a lot of those pills you need to take food with. So why am I going to take—I'm already feeling sick as it is because I have no food in my system. Why am I going to take this pill to get me even more sick because it's just—the pill is just in my stomach."

Lack of support. Respondent 2 stated,

> "Cause at the same time, I've seen when kids that have had that support from their parents, they feel like really confident, you know, to do things and like you know, you're basically like more playful or just like more confident. And you know, they're like more excited cause they have that extra support. When you don't have that, it's just like okay."

Effect of alcohol and street drug on medication adherence. Addiction to drugs and alcohol was reported by some of the respondents as being a contributory factor to poor adherence to their medication by some of the youth. Some of the respondents reported instances when the youth had sold their HIV medication to get money for drugs. When asked the role drugs and alcohol play in medication adherence, Respondent 6 said that "alcohol and drugs is a big issue among our patients . . . it's definitely—and sometimes they do acknowledge that they have issues with drug abuse. And sometimes they look for help, but you always get relapses." Similarly, Respondent 9 reported an incident where the youth living with HIV sold his medication for street drugs: "I think he ends up selling them for higher, but she gives him 60 bucks for it, and he goes, and he buys stuff with that."

Some of the respondents believe that as many as 50% of the youth fail to adhere to their HIV prescriptions because of their indulgence in substance abuse and alcohol. One other respondent (Respondent 3) believes that to improve the rate of adherence to HIV medications by the youth, it is very important to get them off alcohol and substance abuse. This is because not only do the alcohol and substance abuse results in adverse side effects when taken alongside their medications; these substances also impair their judgments often leading them to question

the efficacy of the HIV medications. Sometimes they question the use in taking these ART medications:

> "Not only am I on the streets, you know, sometimes the medication is making me sick. You know, and it doesn't help that I don't have food in my stomach because a lot of those pills you need to take food with. So why am I going to take—I'm already feeling sick as it is because I have no food in my system. Why am I going to take this pill to get me even more sick because it's just—the pill is just in my stomach." (Respondent 10)

Respondent 7 stated,

> "Those times when they're either too high to remember, too drunk to remember. If they're . . . steeped in their drug addiction, they will forget all about their HIV meds and then feel regret the next day or weeks later when they realize they missed about a week of taking their meds. Then you'll see the difference."

Adherence and accessibility to the service organization's clinic. Among the homeless youth population on the issue of medication adherence and accessibility to the clinic for appointments, there are many reasons advanced by their service providers/respondents (who are staff of the service organization), who provide care and services to these youth clients.

Financial. Some of the youth sell their HIV medications for financial reasons. These youth clients sell these medications to fund their drug and alcoholic addictions. According to Respondent 6, "There's a few like my client who was selling medication."

Mental/emotional. In addition to being homeless and battling the HIV disease, several of the youth have mental health issues. According to Respondent 1, "Some of them will stop taking their meds as a form of suicide. That has happened."

The respondents also reported instances where the infected youth would rather have their mental health issues taken care of first before paying real attention to their HIV medications. Respondent 2 stated, "I've even had someone with mental illness that would prefer to take care

of that first, then their HIV. So, they'd rather work on the mental illness medicines and not work with those."

Physical. According to the respondents, some of the youth reported that they stopped taking their medications because they felt better. Respondent 8 stated, "Because they feel better. They'll say I know my body. I feel better! I don't have to take them."

What some of these youth clients fail to understand is that by their nature, HIV medication are made to be taken daily at specified times of the day for the rest of their life. The idea of stopping the medication because they feel better only slowly leads to a weakened immune system capable of acquiring opportunistic infections thereby complicating the HIV and often progressing to AIDS.

Stigma. The stigma associated with HIV also leads some youth living with HIV to consciously or unconsciously skip their medications for the fear of being identified as having the disease. According to Respondent 10, some HIV-positive youth keep their status secret from their partners, friends and families. Unfortunately, people like this will do anything to maintain their secrecy including skipping their medications. Respondent 7 stated,

> "And I think just forgetting or say if there's a—like a living situation that isn't private, and they are hiding their medication or the . . . seeds, then it might not be a good time for them to reach for their medication or to hide it somewhere."

In addition, the fact that these youth clients are homeless also presents some additional challenges. According to Respondent 3,

> "A lot of them go from one place to another place. So, the challenge is having them keep their medications on them. Because a lot of them won't keep them in pill bottles. They'll just keep them in baggies because they're hanging out with people. They don't want them to know that they're HIV meds. They don't want anybody to know they're on medication, so they won't take it."

System. In some organizations/agencies, people living with HIV are given a three months' supply of their medications at a time. While this could be a good idea for people with stable homes, for these homeless youth, it presents a unique challenge as they are most times on the street. According to Respondent 5, "If they're on the streets and they're on that last bottle, well, what if they don't have time to make it all the way to order a new bottle?"

Transient lifestyle. Homeless youth are associated with transient lifestyles. They are constantly on the move, and a good number of them sleep on the streets. It is often difficult to locate them to give them their medications in their last known addresses. According to respondents, the familiar stories by the youth for failing to adhere to their medications include Respondent 6's statement: "I moved and therefore when social services sent me the packets to the new . . . I didn't get it. I lost my medication." Respondent 2 stated, "Yeah, mainly my meds are there, but I was here last night."

Reasons for missed appointments. One of the reasons commonly given by homeless youth for poor adherence to their HIV medications is their failure to keep to their physician appointments. The service organization staff advanced several reasons commonly given by the homeless youth for failing to keep to their physicians' appointments. These reasons include lack of finance, because of the mental state of the youth or incarceration.

Lack of money/transportation. Respondent 1 stated, "Oh, they don't have money. That will be another reason." Respondent 3 stated,

> "They have a hard time even coming here. You know, I just gave a client who I newly diagnosed last Thursday, he came Monday for his appointment, he got his appointment set up for blood draws, but needed six bus tokens to come to his following appointment afterwards because he had three of them. And so, if our supply for that is low, then that affects them."

Respondent 9 stated, "I couldn't get there. No transportation."

Physical. Respondent 2 stated, "There are various reasons. They didn't wake up on time, but that's usually because they're hung over or they're, you know, on some kind of drug or something."

Transient lifestyle. Respondent 1 stated, "Oh, I was out of town. I moved." Respondent 4 stated,

> "Again, they're homeless. They're trying to get their lives together and worry about where they're going to sleep that night. So, them probably getting their spot—and what I mean their spot is finding their place they're going to sleep is probably going to be more important than making a doctor's appointment."

Other barriers to medication adherence. The respondents listed other barriers to HIV medication adherence as follows.

The process and time it takes to be able to obtain the HIV medication. Respondent 5 stated,

> "Probably I think how long it takes to get the medication and then like the enrollment. You know, sometimes up to a month depending on—excuse me—your insurance and stuff like that. So, I would say how long it can take to actually see the doctor and how many times you do need to come to the doctor's visits, you know."

Transient lifestyle/living situation. Respondent 7 stated,

> "And I think just forgetting or say if there's a—like a living situation that isn't private, and they are hiding their medication or the . . . seeds, then it might not be a good time for them to reach for their medication or to hide it somewhere."

Respondent 10 stated,

> "You know, and wonder why I'm taking it, you know. And I also don't want people to know that I have HIV. Some of them, I don't want to take it in front of my friends. A then when I don't do that, sometimes I miss doses. That's some of the responses that they have shared. And then because I'm transient, I can't carry it around in my bag."

Social stressors. Respondent 8 stated,

> Yeah and then the other main thing is just social stressors, like especially in housing. It's like well, you know, I have this person robbed me. I had this person beat me up. You

know, I couldn't find the tokens that you gave me for the bus or somebody took them or—social stressors.

Study Findings

Majority of the respondents reported that the youth have very positive perception about medication adherence. The youth recognize that their HIV medications demands strict adherence, they also acknowledge that faithfully adhering to the medication will ensure a longer and healthier life for them. Respondent 2 stated, "So they know that they have to take it every day. And they do know that from the moment that they stop taking it, their viral load will increase. And therefore, they will have other medical conditions."

The study demonstrated that many of the homeless youth are aware of the problems associated with poor adherence to HIV medications and treatments. As stated by a plurality of the respondents interviewed, their homeless youth clients understand that HIV attacks the immune system, which is meant to protect the body from infections.

According to the respondents, several strategies can help to facilitate HIV medication adherence by their homeless youth clients. Majority of the respondents at the service organization mentioned that the setting of alarms, the use of rewards system/behavior charts, and supervision by family and friends help to facilitate adherence by their youth clients, despite that fact that the identified strategies are not the solution to the problem of adherence. Also, consistent with the findings of this study, there are different measures that can be taken by their clients to facilitate their adherence to HIV medications. However, this same study identified social/emotional problems associated with homelessness and substance abuse as the major barriers to medication adherence by homeless youth. Other factors contributory to the poor

adherence to medication among the homeless youth include forgetfulness, medication side effects, societal stigma attached to HIV and many more.

The study also established that one of the major differences between homeless youth and the general population is their attitude to HIV/AIDS. The interviews held with the staff of the selected service organization revealed that most of the homeless youth in the county where this study was conducted do not regard HIV as a serious health problem. Respondent 4 stated,

> "They don't care. You know, like they don't want to protect themselves anymore and they're not going to protect others. So, it's really bad especially in the homeless population because it's like they don't really want to go spend money on condoms when they could be using that for food or shelter, you know. So that's kind of like on the—not really on their mindset anymore."

For the homeless youth population living with HIV, the most serious public health problems in the county where the research study was conducted were homelessness and substance abuse to the extent that some of the youth sell their HIV medications to buy street drugs, while some who are lucky to be HIV-negative wished they were HIV-positive so that they can be eligible to obtain free housing and other essential resources through the service organization. Respondent 2 stated, "I mean some of the people that we've had who are—who have disclosed to me that they're HIV, some of 'em are, you know, selling their pills sometimes." Respondent 7 stated,

> "They know they can benefit from having HIV. They know [laughs] they can get housing and food and stuff because they have it. Some of them even try to get HIV just for the housing. Yeah. It's if they can survive better, they'll just—they'll get it. They'll just go ahead and contract HIV. Yeah."

Summary

To provide answers to the research questions in this qualitative study, the interview questions closely related to the research questions were re-reviewed and the answers provided by

the respondents were analyzed. The research questions were summarized thus: perceptions of homeless HIV youth regarding HIV, factors besides homelessness responsible for adherence, differences in HIV medication adherence and homeless youth versus general population. Answers to the research questions were extrapolated from the rich data provided by the 10 respondents in this qualitative research. It was then concluded that though homelessness was the major barrier to medication adherence by homeless youth due to their nomadic nature other contributory barrier existed such as social/emotional problems associated with homelessness, substance abuse, forgetfulness, medication side effects, societal stigma attached to HIV, the fear of being labeled as a slut, whore or gay, the side effects associated with HIV medications, and many more.

The study also established that "attitude to HIV" was the major differences between the homeless youth and the general population. The homeless youth do not consider HIV as a serious health problem. Unfortunately, the homeless youth living with HIV perceives homelessness and substance abuse as the primary problem that needs to be tackled and this is evidenced by the facts revealed by the research participants that some of the youth sell their HIV medications to buy street drugs, while some who are lucky to be HIV-negative would rather be HIV-positive to enable them to qualify for free housing and other essential resources.

CHAPTER 5. DISCUSSION, IMPLICATIONS, RECOMMENDATIONS

Introduction

The subgroup of homeless youth living with HIV/AIDS remains a serious public health problem as the HIV epidemic continues to grow among this population. It is estimated that more than one third to one half of the over 1.2 million people living with HIV in the United States who are unaware of their HIV status are either homeless individuals or individuals who are at imminent danger of being homeless (CDC, 2016b). This high prevalence of HIV within this population is primarily due to the engagement of homeless youth in several high-risk behaviors such as substance abuse/addiction, violence, and unprotected sexual activities thereby increasing their risk of contracting and spreading HIV.

This study examined the factors responsible for poor adherence to ART by homeless youth living with HIV. The qualitative research project explored the lived experiences and the perspectives of homeless youth living with HIV/AIDS in a specific county in California, through service providers from a selected service organization. The participants of the study were 10 staff members from a selected service organization comprising of two youth coordinators, a program manager, a mental health therapist, a medical assistant, an enrolment specialist, a housing/clinical supervisor, a prevention specialist, a prevention supervisor/pre-exposure prevention navigator and a HIV blood tester.

After obtaining Institutional Review Board (IRB) approval from Capella University and obtaining signatures on the informed consent form, the 10 participants participated in a 1–1.5-

hour semi structured face-to-face interview sessions during which they answered numerous questions related to their homeless HIV clients. The researcher gained a better insight of the participant's clients lived experiences despite the small sample size of 10 participants, given the methodology used for the study, rich quality data were obtained and NVivo 11 software was used to analyze the data collected to capture the issues that were common between several participants as expressed in their client's experiences. Analysis of all the data collected revealed enlightening findings which showed homelessness and substance abuse as major barriers to HIV medication adherence among homeless youth living with HIV/AIDS and that solving these two problems will go a long way in solving the problem of HIV medication adherence and hence reduce the spread of the disease.

Review of the Research Problem and Purpose

Despite the promises and optimism associated with ART in helping infected individuals manage their HIV disease, it was clear from previous research that treating homeless youth living with HIV presented very serious challenges for public health practitioners and for primary care providers due to their transient lifestyles. However, the purpose of this study was to examine the phenomenon of adherence to HIV regimens among HIV-infected homeless youth in a specific county in California. In examining this phenomenon of adherence, all prior biases and prejudices about the subject matter were suspended to clearly understand the issue of adherence from the standpoint of those closest to the individuals experiencing the phenomenon.

This research study sought to investigate the factors responsible for poor adherence to ART among homeless youth living with HIV/AIDS in other to gain a better understanding of the phenomenon of interest. Being a phenomenological study, all bias, preconceptions and prior knowledge was suspended and the respondents who were interviewed on behalf of the youth

clients experiencing the phenomenon freely described the youth lived experiences and as such the study clearly identified the factors responsible for poor adherence to ART by the homeless youth clients and strongly suggests the need for further research studies.

Significance

Again, according to the words of Shubber et al. (2016), it is still a puzzle that despite more than two decades of research on adherence to ART and even though more than 17 million HIV-positive people rely on ART for their treatment, adherence has continued to pose a significant challenge. Conducting a research geared specifically to investigate the phenomena of interest from the perspective of the individual actor or the group about the lived experiences of the homeless youth in relation to their HIV management and medication adherence offered the best approach to determine why adherence has continued to pose a significant challenge among homeless youth living with HIV/AIDS. The concept of phenomenology unraveled findings that have not been imagined or thought about by clinicians, public health officials or other service providers.

This qualitative research has certainly contributed to current practice by gaining a better understanding of the barriers and challenges hindering homeless youth living with HIV/AIDS from adhering to the strict regimen of antiretroviral therapy. The findings of this study should begin conversations and coalitions among healthcare providers, service providers, governmental and nongovernmental agencies to collaborate on how to help homeless HIV youth halt the spread of the disease.

Analysis, Synthesis, and Evaluation

The research study was conducted using qualitative phenomenological research method with the objective of factually describing the essential meaning of the homeless youth lived

experiences in relation to their HIV management and medication adherence. The process required data collection, integration, assessment and interpretation. The researcher completely embraced the concept of phenomenology, allowed themes to emerge directly from the data collected, utilized the results of the process, evaluated the data and provided answers to the research questions reflecting the populace studied.

The process started with interviewing 10 identified HIV/AIDS service organization staff members through a face-to-face interview. After signing informed consent, each participant put in their best in answering the interview questions. They were very open and conducted themselves professionally. The experiences and perspectives shared by the participants were within the purview of their profession as first line service providers. The interviews were recorded using an audio tape recorder and then later transcribed word for word on paper.

Data was analyzed using NVivo 11 software which involved finding frequently used and meaningful words and then categorizing and making sense of the essential meanings of the phenomenon to extrapolate themes and topics to draw out key issues being expressed by the participants. Synthesizing the numerous data provided by the 10 service organization staff members provided first-hand information which contributed to the synthesis of a pool of ideas that helped the researcher arrive at the study findings.

Implications of Findings

The primary goal of ART treatment is to prevent the high rate of morbidity and mortality associated with HIV especially among the homeless youth population. Several studies have shown that nonadherence or poor adherence diminishes the efficacy of ART and increases the rate of hospitalization, mortality and morbidity among people living with HIV/AIDS. Despite advancement in medicine and science, the spread of HIV/AIDS among homeless youth has made

no head way as it continues to remain a public health issue and a serious focus for health care practitioners. The findings from this study uncover specific facilitators and barriers to adherence faced by homeless youth living with HIV/AIDS. It goes further to unravel lived experiences shared by those closest to those experiencing the phenomenon under study that may not have been imagined or thought about by clinicians, public health officials or other service providers.

This study was intended to help public health officials understand the identified facilitators and barriers to adherence among homeless youth living with HIV/AIDS. Understanding these variables and how they interconnect will assist public health officials as well as other stakeholders in advocating for more funds to provide stable shelters/homes for the homeless youth while tackling HIV/AIDS medication adherence as well as the prevention and spread of HIV/AIDS disease in the county where this research was conducted in California and beyond.

Discussion of the Conclusions in Relation To the Literature in the Field

Several studies (Allen et al., 1994; Bangsberg, Tulsky, Hecht, & Moss, 1997) have studied the issue of medication adherence among the youth population living with HIV/AIDS. These various studies basically asked the study participants to recall and discuss their rate of adherence to their HIV medications. This research study is unique, because it employed the use of qualitative methodology, using a descriptive phenomenological approach to study the lived experiences of HIV-positive homeless youth. Previous studies focused on adherence, while this study focused on the unintended consequences and behaviors that occurred because of this population's HIV/AIDS diagnosis.

Data was obtained by conducting one-on-one, face-to-face, in-depth, semi structured interviews not directly with the youth population experiencing the phenomena but rather with the individuals closest to those experiencing the phenomena. In this research, the study relied on the staff members of the service organization who worked closely with these youth clients providing counseling, support and various life sustaining services, who by their close interactions have the direct knowledge to narrate the youth lived experiences. These service organization staff were the primary participants interviewed because Capella University's IRB deemed the youth participant's vulnerable homeless kids and thus it was considered unethical to have contact with them.

The research literature on the issue of adherence among homeless youth, though sparse, identifies major barriers to optimum HIV/AIDS medication adherence. The identified barriers included forgetfulness, fear of disclosure, food issues, medication side effects, substance abuse, transient lifestyle, and not keeping their medications on their person. This study has added to the existing body of literature regarding the barriers to optimum HIV/AIDS medication adherence because it provided information about the youth's unintended payoffs or motivators for the youth to be HIV-positive and to continue in a state of nonadherence. Evidence from this study has shown a disturbing trend among homeless youth living with HIV/AIDS regarding medication adherence which will require further studies. According to several of the service organization staff interviewed during the study, this disturbing trend consists of a steady rise in the number of homeless youth who trade their HIV/AIDS medications for cash money and for drugs.

Similarly, some service organization staff members reported that some homeless youth who come for HIV testing get disappointed when they are told that their HIV status is negative. According to the respondents, these youth clients believe that a positive HIV status will provide

them opportunities for accommodation and some basic needs of life. This poor/negative perception among some of these youth on the dangers posed by HIV/AIDS does not bode well for the effort to control the spread and effect of the disease among homeless youth population. This is one area that will call for further studies as a way of checkmating the spread of the disease within this population and within the society in general.

This study also brought to focus and clarity on how the social and emotional environment of an organization can contribute to the success of homeless youth with reference to improving their adherence to their HIV medications and improving their overall HIV status. At the service organization where this study was conducted, a sizeable number of the staff are living with HIV/AIDS. These service organization staff share similar experiences and history with most of the youth, and thus it is much easier for the youth to understand and relate with them. The selected service organization creates a very warm, friendly, supportive and nonjudgmental environment which encourages the youth to accept the help offered with limited hesitation.

At this selected service organization, majority of the staff instill trust and build a strong relationship with the youth and as such act as secondary case managers. The service organization staff keeps tabs on the youth, links them to care and make sure that they attend their clinic appointments, attend group sessions, take their medications and have all the basic necessities that will facilitate their medication adherence.

Limitations of the Study

Although the study provided great insights about the struggles of homeless youth living with HIV/AIDS regarding adhering to ART regimen in other to control and stop the spread of the disease. This study was faced with a few limitations. The major limitations were as follows:

1. Recruitment and interview of study participants from a single organization. The small nature and the concentration, recruiting and interviewing of all the study participants in a singular geographical setting and from just one service organization in California could limit the ability to generalize the findings of the study to all homeless HIV-infected youth throughout the country.
2. Commitment of the service organization. The academic researcher also anticipated some challenges regarding support from the California based nonprofit organization where all the homeless youth are clients. The commitment of this organization to participate in the research did not change or flicker at any time during the research; however, the researchers plan to interview the doctors was impossible because of their very tight schedule and the vast amount of patient they see. Of note, an hour-long interview took away time from their busy schedules. This limitation was not within the control of the researcher; however, the researcher did everything ethical to assure the organization of the possible benefits of the study.
3. Interviewing the providers and not the patients. The original plan of the academic researcher was to conduct a quantitative research using questionnaires, interviews and study group sessions to gather data directly from the homeless youth living with HIV/AIDS. However, Capella University's IRB deemed the youth participant's vulnerable homeless kids and considered it unethical to have any contact with them. Based on this, the researcher had to develop a justification for a phenomenological study using personal interviews to collect data from individuals closest to those experiencing the phenomenon which were the staff members working closely with the clients.

4. No gold standard for measuring optimal HAART medication compliance and adherence. Till date, there are no known established gold standard of measurement for measuring optimal HAART medication compliance and adherence (Williams, Amico, Bova, & Womack, 2013). The implication of this was that the researchers understanding/definition of patient's adherence were based on a whole lot of factors such as patient's self-reports, drug counts, and many more (as discussed above) which are not 100% reliable.
5. The researcher being a nurse. The researcher being a public health nurse and a practicing bedside registered nurse with prior vast knowledge about HIV/AIDS treatment and management posed a little bit of a limitation around the researcher conducting and writing this research study without infusing her own prior knowledge and experiences into the reported experiences of the study participants. Being a phenomenological study, the researcher had to suspend every past knowledge, and experiences by putting away prior beliefs, feelings and perceptions to gain new knowledge and to truly understand the phenomenon of interest from the standpoint of those experiencing it or from those closest to those experiencing it.
6. The sample size and geographic setting. The sample size of 10 in consistency with phenomenological research was approved for this qualitative research study; however, generalizations to a larger population may not apply. Again, the geographic setting and small sample size was not redesigned to address this limitation because phenomenological research studies support the study of a small number of participants through broad engagement to achieve patterns and useful connections (Goulding, 2005).

Recommendations

There is no doubt this study has contributed to understanding the barriers faced by homeless youth living with HIV/AIDS in terms of their ART regimen adherence. The study results showed that homelessness play a more significant role in impacting these individual's ability to cope with being HIV-positive. The study results also support the notion that homelessness is a bigger obstacle when compared to HIV/AIDS among homeless youth living with the disease.

From this research, 70% of the participants stated that their clients do not consider HIV/AIDS a serious problem in the county where the research study was conducted. It can therefore be posited that how seriously an individual views HIV/AIDS may influence medication adherence. This research therefore provides direction for future research. If persons living with HIV/AIDS are homeless and have nowhere to lay their head, would they adhere to any type of medication regimen adherence or compliance? Unfortunately, the answer is clearly no.

Would it be feasible to expect that persons who have no housing be willing to adhere to HIV/AIDS medication regimen? Do persons who do not see HIV/AIDS as a problem in California take the disease seriously and be cautious about spreading it from one person to another? Do homeless persons who are willing to get infected with HIV/AIDS to qualify for free housing care so much about HIV/AIDS as a disease? Do persons who sell their HIV/AIDS medication for cash money because they are homeless and hungry care about HIV/AIDS and curtailing the spread? The fact remains that it will be very difficult to control the spread of HIV/AIDS if the focuses of homeless youth living with the disease are to secure a place for their heads, food for their stomach, rather than adhering to HIV medication regimen to better control the spread of the deadly disease.

The findings from this research study exposed why homeless youth living with HIV/AIDS find it difficult to adhere to their ART treatment regimen and therefore recommend further research in ways to curb homelessness before addressing the issue of medication adherence in lieu of controlling the spread of HIV/AIDS. Although it will be very challenging to control the spread of HIV/AIDS among homeless youth living with the disease, the findings of this study indicate the need for continued research in preventing the spread of HIV among this population because of the issue of transient lifestyles, poor adherence to HIV medication regimen and the ease of spreading HIV rather than preventing the spread.

The quicker homelessness is addressed within youth living with HIV/AIDS, the more realistic it will be to focus on medication adherence and ultimately prevent the spread of HIV thus keeping the HIV-positive healthy and the HIV-negative negative. This research therefore provides direction for future studies. This researcher believes that a study directed towards navigating the issues of homelessness may serve to accomplish preventing the spread of HIV/AIDS among homeless youth living with the disease.

Summary

Every aspect of this research journey has ushered interesting but challenging experiences. The first challenge started with finding an organization that catered for HIV-positive homeless individuals who were willing to grant the researcher permission to conduct this research. The researcher found one after five trials. The researcher's intention was made known about wanting to work with the clients being served by the service organization and permission was granted but unfortunately, Capella University's IRB deemed the research population vulnerable and encouraged the researcher to interview the staff who catered for the client's rather than the client's themselves. The researcher immediately reformulated the survey instruments and

research methodology tailoring it towards the service providers and not their clients. The interviews took a long time to conclude because the researcher had to schedule the interviews around the busy schedules and availability of the staff members who had to be pulled away from work and for the most part, the interviews were conducted during their personal breaks.

Adherence to HIV medication continues to be a serious public health challenge for homeless youth in the state of California. Even though homeless youth living with HIV/AIDS know the efficacy of ART regimen in the management of the disease, several factors prevent them from keeping up with the strict demands of ART regimen. This problem with adherence makes it difficult to achieve the goal of reducing the spread of the disease within the homeless youth population.

As Respondent 5 stated,

> "They don't care. You know, like they don't want to protect themselves anymore and they're not going to protect others. So, it's really bad especially in the homeless population because it's like they don't really want to go spend money on condoms when they could be using that for food or shelter, you know. So that's kind of like on the—not really on their mindset anymore."

One of the biggest surprises gathered by the researcher were that some of the clients were selling their HIV medications for cash money to buy drugs or to buy food and that some others were willing to acquire HIV, so they could qualify for free housing. Despite the wake-up call about some of the youth selling their HIV medications and HIV-negative individuals trying to acquire HIV so that they can have free housing and other free services, I was further thrown off guard to hear some participants report that their clients do not see HIV as a problem. To improve HIV medication adherence and reduce the spread of HIV among the homeless youth population, serious effort would have to be made to address the problem of homelessness and all the social/emotional problems that are associated with it.

Reflections

To say the researcher was impressed with the study participants of this research is simply an understatement. The researcher cannot begin to narrate how touched she was to meet numerous staff members of different disciplines and ages of the selected service organization; some of who started doing these jobs at age 18. They seemed all happy about their job and spoke highly of their organization. One of the interview questions had asked the 10 service organization staff members what gave their clients hope despite being homeless and living with HIV/AIDS. Here is what each participant had to say; their answers were very informative and thought provoking.

> **Respondent 1.** "They get hope from meeting other young men or other people who are long-term survivors. Persons like myself who have been living with it for almost 20 years. They'll meet me and then I'll impart into them and they're like oh, my God. Okay, so I can succeed. I can get a job. I can get a degree. I can do this. I can find love. So when they see people who are long-term survivors who are living healthy and happy, it encourages them and it makes them feel better about themselves."

> **Respondent 2.** "What gives them hope is seeing other positive folks moving forward. I think what also gives them hope outside of the service organization and the other agencies that they may encounter is that, you know, the agencies—they see that the agency cares about them. And I think when they connect with or see that certain staff or there are some staff members at the agencies that also live with it and are doing pretty well, that they can gravitate to them, get a little hope from looking at those folks as well, you know."

> **Respondent 3.** "I am positive. So, I kind of tell them, you know, my story and my background in the HIV field. So, it kind of gives them that sense of comfort. Like if they do have questions, I can answer them based on the medication or how long treatment takes. And I'm just able to speak from more of a personal level so I think it gives them that kind of that bond."

> **Respondent 4.** "They feel a little bit more hopeful for where the medicine and the treatment is going with HIV because there were times when people were falling off, you know, just dying."

> **Respondent 5.** "Us, their support system, you know, other resources place—you know, when they know they have someone they can go to for things."

Respondent 6. "What gives them hope is the fact that they will find a place like us that will help them try to meet their basic—not their basic needs, but some of their needs. Like if we help them with housing, we help them with food, we help them with their medical insurance and getting the care that they need. So, they feel like okay, and also the fact that it's always a program that will help them to get their meds. So, it's all of that."

Respondent 7. "I think the support that we do here and that I do cause honestly, I kind of go above my job. You know, we're very clinic-y hours, 9 to 5. And because I'm—you know, I'm very close to the age of a lot of them and I've been doing this work since I was 18. And so, for like my clients on my caseload, I give them my personal number. And I let them know if you guys want to call me or text me outside of work, you can do that. Cause I know that if they are, you know, it's not going to be on anything else and if it is, I have to set that boundary. But a lot of us now in 2017, we reach out in different ways, and I want to be available in those ways."

Respondent 8. "I think the person that they come into contact with, like either the counselor or the tester or even like the mentor/mentee relationship. I think really if you're really—you know, people in their field have a lot of clients and they deal with a lot of clients, but you know, there's a way of dealing with a client like whether it just be a client or, you know, there's a certain way you need to act with them. You know, you can't just act like it's your job and, you know, once they leave, okay, bye. You know, you need to have that how are you doing today? Like kind of a—like in a counseling session, once I'm doing the test, you kind of have to develop like some kind of, you know—I mean not so much of a friendship, but an understanding. You know, ask them how they're doing. You know, where they're not just has to be with HIV, but you know, family, living situations, all of that. You need to kind of tie that in because then they feel like okay, you know, I can go and talk to this person. Maybe not just about my HIV, but you know, he knows about my substance abuse or my family situation or—so you kind of have to have that relationship so they can keep coming back."

Respondent 9. "I think agencies like these gives them hope."

Respondent 10. "I would like to say that their success—their success. And what I let the clients know is, you know, you're—you can do it if you believe in yourself, you know. And the challenges with that is sometimes you have to keep telling them and keep telling them. And I also let them know because a lot of them are substance users, so they've been clean for about three weeks, and then they have a slip. Don't beat yourself up over it because you know why? You're homeless, you're living on the streets, and you're a person of color. You're already getting beaten up by society, right? Why are you going to beat yourself up more? Pick yourself up, dust yourself off, and move on."

The researcher truly enjoyed the interview sessions with the staff members of the selected service organization used in this research study.

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APPENDIX A. STATEMENT OF ORIGINAL WORK

Academic Honesty Policy

Capella University's Academic Honesty Policy (3.01.01) holds learners accountable for the integrity of work they submit, which includes but is not limited to discussion postings, assignments, comprehensive exams, and the dissertation or capstone project.

Established in the Policy are the expectations for original work, rationale for the policy, definition of terms that pertain to academic honesty and original work, and disciplinary consequences of academic dishonesty. Also stated in the Policy is the expectation that learners will follow APA rules for citing another person's ideas or works.

The following standards for original work and definition of *plagiarism* are discussed in the Policy:

> Learners are expected to be the sole authors of their work and to acknowledge the authorship of others' work through proper citation and reference. Use of another person's ideas, including another learner's, without proper reference or citation constitutes plagiarism and academic dishonesty and is prohibited conduct. (p. 1)
>
> Plagiarism is one example of academic dishonesty. Plagiarism is presenting someone else's ideas or work as your own. Plagiarism also includes copying verbatim or rephrasing ideas without properly acknowledging the source by author, date, and publication medium. (p. 2)

Capella University's Research Misconduct Policy (3.03.06) holds learners accountable for research integrity. What constitutes research misconduct is discussed in the Policy:

> Research misconduct includes but is not limited to falsification, fabrication, plagiarism, misappropriation, or other practices that seriously deviate from those that are commonly accepted within the academic community for proposing, conducting, or reviewing research, or in reporting research results. (p. 1)

Learners failing to abide by these policies are subject to consequences, including but not limited to dismissal or revocation of the degree.

Statement of Original Work and Signature

I have read, understood, and abided by Capella University's Academic Honesty Policy (3.01.01) and Research Misconduct Policy (3.03.06), including the Policy Statements, Rationale, and Definitions.

I attest that this dissertation or capstone project is my own work. Where I have used the ideas or words of others, I have paraphrased, summarized, or used direct quotes following the guidelines set forth in the APA Publication Manual.

Type Learner name and date	CHINYERE IWUAGWU, 8/17/2017
Mentor name and school	ROSSLYNN BYOUS, DPA, PAC, Capella University

APPENDIX B. INTERVIEW QUESTIONS

1. INTRODUCTION/DEMOGRAPHICS

a. How do your clients typically identify themselves?
b. How old is the average client on your case load?
c. What is the highest level of education that your clients have completed?
d. What ethnic group does majority of your clients identify with?
e. What are the primary languages of most of your clients?
f. What is the employment status of most of your clients?
g. How would you describe the relationship status of majority of your clients (single, married, with same-sex partners, etc.)?
h. What percentages of your clients are married or have kids?
i. Other than the service organization, do your clients have other support systems?

2. ACCOMMODATION/RESIDENTIAL STATUS

a. What percentage of your clients consider themselves homeless or would you consider homeless?
b. Where do majority of clients live (hotels, shelters, on the street etc.)?
c. What is your estimation of how long they usually stay at a particular location (i.e., reside in one place)?

3. ATTITUDE

a. How would you describe their attitude to the fact that they are living with HIV/AIDS?
b. Do you know whether they freely discuss their HIV/AIDS status with any one?
c. If yes, who do they usually discuss their status with?
d. From your interactions with them, do they consider HIV/AIDS a serious problem in this county in California?
e. What are your clients' understandings of HIV?
f. What are your clients' knowledge about HIV transmission?
g. About how many years have your clients been living with HIV?
h. For them, what is it like to experience HIV?
i. How has HIV influenced their lives?
j. How has the diagnosis of HIV changed their lifestyle?
k. What gives them hope?

4. MEDICAL HISTORY/BEHAVIORAL HEALTH

From your interaction with your clients, what have been the major social/emotional issues that have hindered their adherence to their ART/medications?

a. In your opinion, to what effect do you think any of the following have been a factor in the failure of your clients to adhere to their ART?
   I. substance abuse
   II. mental illness
   III. alcohol
   IV. sexual abuse
b. Besides the four social/emotional issues mentioned above, what other social/emotional issues have been contributory to the failure of your clients adhering to their ART treatments?
c. Are there occasions when drugs or alcohol use has prevented your clients from taking their medication/ART?

5. ADHERENCE & ACCESSIBILITY TO THE CLINIC

a. What is the typical length of ART treatment for your clients?
b. Are you aware of any of your clients who take traditional medicine in combination with ART for HIV treatment? (About what percent?)
c. What are the reasons clients' give for not adhering to their ART Treatment?
d. What do they say are common reasons for missed appointments?
e. What form of transportation do clients usually use to get from their residence to the clinic/organization?
f. Please discuss any factor(s) that your clients believe affects their adherence to ART medication or appointments?

6. EXPERIENCE TAKING ARTs

I am interested in learning about your clients' experiences taking medication for their HIV.

a. Please tell me the events that led your clients to start taking these ARTs. [Probe how did they find out about them, what did they know about them, who or what persuaded them to look for medication.]
b. How has taking ARTs changed their lives? [Probe for both positive and negative changes.]
c. How do they think these ART medications work in their body? [Probe for: does ART provide cure? What do they think will happen if they stop taking ART? What will happen if they don't take ART every day?]

7. PERCEIVED STIGMA

There are a lot of social and emotional aspects of living with HIV/AIDS. Some people have had bad experiences because they are HIV-positive, and others are afraid that people will react differently because of their HIV diagnosis.

a. What are some perceived stigmas that have been reported by your clients?
b. Have any of your clients reported being treated differently because they are HIV-positive? Tell me about that.

8. PERCEIVED SELF-EFFICACY TO ADHERE

There are a lot of situations that people talk about that makes it difficult for people living with HIV/AIDS to take their pills every day and on time. Could you discuss some of the situations that your clients have discussed with you?

9. SKILLS AND STRATEGIES APPLIED FOR TAKING MEDICATION

Some people do things so that they are better able to remember to take their ART medications every day and on time. Are you aware of any strategies some of your clients use to remember to take their medications/ART?

10. PERCEIVED SIDE EFFECTS

What side effects to ARTs have your clients reported or complained about?

11. PATIENT–PROVIDER COMMUNICATION

a. What is your relationship with the clients? How would your clients describe the patient–provider communication?
b. How helpful has this service organization been to your clients since their diagnosis of HIV/AIDS?
c. What role do you think government agencies play in helping people with HIV adhere to their ART treatment medications?
d. Is there anything else that this service organization can do to better to support your clients, and other people taking ARTs?

12. CONCLUSIONS

Now I have asked you all my questions. Do you have anything else you would like to share about your experiences as a person providing care and support to people living with HIV or especially as it concerns their adherence to their ARTS/medications?