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Identifying Barriers to Adherence for HIV+ Patients Placed on Renal Dosing

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Identifying Barriers to Adherence for HIV+ Patients Placed on Renal
Dosing

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B.A., University of Connecticut, 2006

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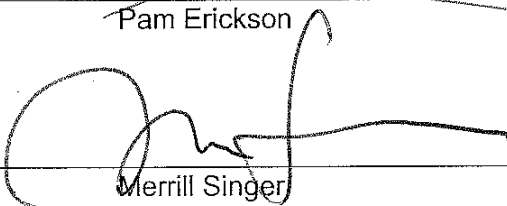
Master of Arts Thesis


Identifying Barriers to Adherence for HIV+ Patients Placed on Renal
Dosing

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List of Acronyms:

HIV	Human immunodeficiency virus
AIDS	Acquired immunodeficiency syndrome
CD-4 cells	A type of white blood cells
HAART	Highly active antiretroviral therapy
IDU	Intravenous drug user
IMB model	Information, motivation, behavior skills model of adherence
AA	African American
LifeWindows	Adherence research project delivered by a computer program by the same name
ARV	Antiretroviral
CHIP	Center for Health, Intervention, and Prevention
NRTI	Nucleoside reverse transcriptase inhibitor
MSM	Males who have sex with males
RD	Renal dosing group
SP	Total sample population

Introduction:

The association between HIV and renal dysfunction is well documented in the HIV literature (Wyatt & Klotman 2006, Gupta et al. 2005 as cited by Mocroft et al. 2007). A syndemic relationship can exist between these two serious health conditions (Singer 2009). While adherence to HIV medications is important, it can be difficult for a person who suffers from co-morbidity. In this thesis I examine possible barriers to adherence for HIV+ patients placed on renal dosing regimens. The data for this research came from a larger psychological study on medication adherence. Of the 590 patients in the study, 12 patients had their HIV medications changed to a renal dosed regimen. All 12 patients suffered from renal toxicity from the ARV medication, Tenofovir. The purpose of this thesis is to identify whether there are specific barriers to adherence that the patients on renal dosing identified and those on normal dosing schedules did not. The hypothesis of this thesis is that the switch to a renal dosed regimen will increase the barriers and difficulties patients have in adhering to their ARV medications.

This thesis begins with an examination of the literature on HIV and renal dysfunction, paying special attention to renal failure due to nephrotoxicity. Nephrotoxicity is the toxic effect that some medications have on the kidneys. Then, this thesis looks at participants' responses to a survey that measured ARV medication adherence. From this data, this thesis analyzes and discusses findings to determine if any trends exist between specific groups of participants.

The data for this thesis came from a longitudinal, psychological investigation of barriers to adherence for ARV medications, called the LifeWindows Project (Fisher et al. 2011). The research project ran from March 2006 to March 2008 at five HIV clinics located in the state of Connecticut. Participants could only participate if they were patients of the clinic. Patients participated in the study for 18 months and could complete a survey only once per month.

I worked on this study as a research assistant. While I was not involved in the design of the study, my duties included the retention of participants and maintenance of participant information. During the study, I noticed that some patients had their medication regimens changed from taking the medications every day, to only taking the medications once or twice a week. This was strange because ARV regimens require patients to take the medications everyday in order to be effective. After investigating this occurrence the team found the medication, Viread, caused kidney problems in some of the patients. With the kidneys unable to function, these patients needed to undergo dialysis treatments. Due to the way the body excreted the medication from the kidneys, the patients had to lower their ARV intake or the medication would become toxic.

At the onset of the study, the medical community was unaware about the side effects incurred from prolonged use of Viread, which includes nephrotoxicity. Since that time, around 2% of the HIV population in the United States suffer from

this adverse reaction (Hamzah & Post 2009). There is still more to learn about this issue, especially if other medications can cause nephrotoxicity.

Renal dosing is a strategy a provider utilizes when a particular medication causes nephrotoxicity. The provider lessens the number of prescribed doses in order to minimize medication toxicity in the patient. This thesis examines the barriers to adherence for these participants by examining their responses on demographics and barriers to adherence. Due to the small sample size this thesis cannot represent the greater HIV population. Instead, this thesis intends to highlight areas that should be further investigated and tested. Learning about the barriers that these participants faced can help future researchers focus their efforts in addressing barriers to adherence for HIV+ patients placed on renal dosing.

Background on HIV and ARVs

History of HIV:

In the early 1980s, the human population became acutely aware of HIV. The virus quickly spread worldwide, and this serious health problem became a global pandemic. To date, the virus has infected over 33 million people worldwide (WHO: Global Summary of the HIV/AIDS epidemic, December 2008). Like many diseases, the virus has affected developing nations the hardest. However, HIV is still a serious problem in developed nations like the United States. To date, HIV claimed the lives of over half a million Americans, disproportionately affecting poor and minority populations (AVERT: HIV and AIDS statistic summary).

HIV is among the deadliest of diseases because the virus enters a host and attacks the CD4-cells in the body. These cells are integral in the maintenance of a healthy immune system. The CD4-cells combat infections and foreign organisms that enter the body. The virus can alter the genetic coding of the CD4-cells, forcing them to replicate versions of the virus instead of creating more

CD4-cells. Over time the virus destroys the CD4-cell. With a low number of CD4-cells in the body the host cannot fight off infections and becomes vulnerable to opportunistic infections and diseases.

In the beginning of the HIV epidemic, HIV+ patients viewed infection as a death sentence because providers lacked medications to combat the virus. This led to compromised immune systems for the patients. Scientists searched for ways to combat HIV for years before they found an effective pharmaceutical combination -- the highly active antiretroviral therapy (HAART) -- that transformed AIDS from a death sentence to a chronic disease (Kak et al. 2000).

Yet, the first ARV medication was not available until 1987, with the introduction of AZT, the first FDA approved medication, for the treatment of HIV (FDA: HIV/AIDS Historical Timeline). Since then, newer and more effective medications are used to fight the virus. In 1996, the medical community started to combine aggressive ARVs into medication regimens, giving rise to HAART (Moore et al. 2005). With the effectiveness of the new medications and medication regimens, mortality rates dropped as people lived with HIV infection (Hooshyar et al. 2007).

Although HAART is effective in battling HIV and keeping the individual alive, there is no cure for HIV. The medications do not destroy the virus. Rather, they keep the virus at bay by either preventing it from entering the CD4-cells or by preventing its replication.

Adherence to Medication:

Since HAART cannot destroy the virus, an HIV+ patient is infected for life. The patient must take the medication every day in order to keep the virus from destroying the CD4-cells and replicating itself. The virus can mutate when a patient misses doses of his/her medication. HIV, as a type of RNA virus, produces high yields over short periods of times. This high replication rate greatly increases the rate at which mutations occur. HIV can rapidly respond to new challenges and environments, such as a missed dose of an ARV medication

(Domingo & Holland 1997). If any of these new mutated versions of the virus become immune to the medication, resistant strains of the virus will make existing medications ineffective. Such drug resistance renders the particular medication the patient took no longer effective in stopping HIV replication. If the patient passes the mutated virus to another person, the newly infected person will contract a drug resistant strain, making that particular medication ineffective for both parties (Rintamakami et al. 2006, Fogarty et al. 2002).

Thus, HIV+ patients must adhere to their medication regimen in order for the treatment to be effective. Poor adherence is the number one cause of treatment failure for chronic diseases, especially HIV (Cressey & Lallemand 2007). A 95% adherence rate is necessary to maintain medication efficacy and prevent the virus from developing resistance to the medication (Bautista-Arredondo et al. 2010).

Since adherence is of the utmost importance, health care providers should be involved in their patients' care. The providers must also ensure that their patients can adhere to medication regimens before prescribing HAART by observing the patients' medication-taking behaviors (Hawkins 2010). Adherence to HAART is the determining factor in whether or not the therapy will be effective (Barfod et al. 2006). Unfortunately there is no way for doctors to determine which of their patients will not adhere to HAART. Therefore, providers must understand the barriers that cause their patients to be noncompliant, and identify and address these barriers so that patients can adhere to their medications (Fogarty et al. 2002, Bangsberg et al. 2001).

Barriers to Adherence:

Before providers can understand the barriers to adherence they first need to understand the process of living with HIV and how barriers develop. Some of these factors are external and lie outside of the patient's control. Many of these external factors develop out of economic, social, and political issues (Bautista-

Arredondo et al. 2010). The development of these factors is a result of HIV's concentration among marginalized populations such as the poor, under-educated, intravenous drug users (IDUs), people of color, and prisoners. These groups also suffer from negative social stigma, which denies them economic gains and political control to address issues in their lives (Rintamakami et al. 2006). Members of stigmatized groups have less access to resources and may have a harder time obtaining medications to adhere to. Many of these patients lack the social support structures necessary to counteract these factors (Maskovsky 2005, Hill et al. 2003). To help these patients adhere to their medications, researchers, doctors, and public health officials designed numerous interventions to address these barriers and improve adherence.

Other external factors that affect medication adherence lie not with society but with the provider. At the time that the data for this thesis was collected, all but one of the HAART regimens included multiple HIV medications. No single regimen works for every patient. Sometimes the doctor does not prescribe an effective regimen or the correct dosing because medications react differently in different people (Cressey & Lallemand 2007). The doctor may have to try several different regimens in order to find one that will work for the patient. Each time a change is made in a medication regimen, it increases the difficulty for the patient to adhere to the regimen (Vrijens & Urquhart 2005).

Adherence is also affected by the relationship between the patients and their providers. Patients that trust their doctor, and the prescribed therapy, are more likely to be adherent (Barfod et al. 2006, Remien et al. 2003). It is not uncommon for patients to keep information, such as their adherence, from their providers (Hill et al. 2003). Health care providers need to gain the trust of their patients when prescribing medications. It is vital that providers take a patient-centered approach to caring for their patients (Stein 2009). Even successful patient-provider relationships can dissipate over time (Hunt et al. 1989).

While there are many external factors that the patient does not have control over there are internal factors that the patient can control. These internal factors are associated with the beliefs a patient has, the behaviors a patient exhibits, and the actions a patient takes. These internal factors can create adherence barriers that can affect patients, regardless of their socio-economic status. Doctors, researchers, and patients must identify and overcome these barriers for viral suppression to occur (Chesney 2000). Interventions to increase patient adherence developed from a better understanding of these barriers (Berg et al. 2004, Bogart et al. 2010). Some of these interventions use discussion and education to change a patient's beliefs and behaviors (Mills et al. 2006). The provider can work with the patient and educate him/her on the medications and on adherence techniques (Roberts 2000). Researchers also developed interventions that patients can use at home (Jerant et al. 2005).

Even after a provider identifies the internal and external factors that affect adherence, he/she still needs to understand the complex barriers that a patient lives with. These barriers are broad and deal with a wide range of aspects of living with HIV (Chesney 2000). Each patient is unique and has different experiences, so it is difficult to determine if a given factor will cause a barrier for a given patient. Researchers found four factors that are salient predictors of noncompliance, which include the patient's living situation, psychological health, access to medications, and history of substance abuse (Fisher et al. 2006). These factors comprise the IMB model of adherence to HAART. If a patient has difficulties with any of these factors, barriers to adherence usually follow. This model is linked with the individual's health outcomes, which include his/her physical health, quality of life, and current HIV status (Fisher et al. 2006).

Increasing Adherence: The IMB Model:

While some patients have stable living situations and access to medications, and lack psychological issues, and substance abuse problems, these patients can still possess barriers to adherence. Trying to identify the barriers to adherence

for these patients is extremely difficult. One tool that is effective is the Information, Motivation, and Belief (IMB) model of adherence (Fisher et al. 2006). By using this model, providers can better understand, predict, and promote adherence with their patients. With the IMB model the providers can examine the information patients possess about HIV and their medications; the motivations and beliefs patients have about the virus, their medications, and what it is like to live with HIV; and the behavioral skills the patients possess and their ability to adhere to their medications. When patients are “well informed, motivated to act, and possess behavioral skills required to act, adherence can be maintained” (Fisher et al. 2006). It is important to take the concept of culture into account when looking at the factors that affect adherence. Cultural practices and beliefs will vary, which can change the understanding of these factors. When utilizing the IMB model of adherence one must understand the culture to determine the model-based elements of the IMB model that are appropriate (Fisher et al. 2006). The IMB model of adherence helps providers identify adherence barriers for patients who may not have any of the four major factors associated with non-adherence as discussed above.

When using the IMB model it is important for providers to remember that life with HIV is not uniform for all people. Different groups of people will face different issues, and as a result may have different barriers, and the barriers associated with one group may not affect another group. For example, the barriers that affect IDUs are quite different from those that affect other groups (Krusi et al. 2010). When researching medication adherence providers and researchers should always look for other factors that can affect adherence. To do so the providers and researchers need to comprehend what life is like for the patients and understand the patients’ values, judgments, habits, and behaviors (Max & Sherer 2000).

On the surface, adherence appears to be cut and dry. A provider wants to know if his/her patient took the medications as prescribed. When a patient is not

adherent to his/her medication the medical community considers the patient to be noncompliant. The language of compliance shows the power dynamic that the provider has over the patient (Trostle 1988). The provider is the holder of knowledge and the patient is subject to the rituals of the healthcare setting (Papen 2010). This noncompliant point of view is only from the doctor's and is devoid of the patient's perspectives. Noncompliance can make it appear that the patient does not take care of himself/herself, and that the patient lacks agency. Yet, there are things that the patient can do for his/her health that do not include HAART, which a provider may not take into account. The patient can attempt to manage HIV in ways that are not assessed by the clinician (Trostle 1988). Similarly, the language of noncompliance can place blame on the patient and the provider may assume that the patient 'disobeyed' his/her instructions (Rousse 2010). Yet, the patient could be a victim of structural violence due to discrimination and economic inequality (Scheper-Hughes & Bourgois 2004 as cited by Rousse 2010, and Chapman & Berggren 2005). Thus, many in the medical community use the language of adherence, with the hope that the power differences will not be present in the language. "The shift from compliance to adherence demonstrates a growing awareness of power relations in doctor-patient interactions and of the frequently cited distrust in institutions such as biomedicine" (Leibing 2010).

One strategy that providers can use to better understand patients is to become aware of the cultural aspects of their patients' lives. The hope is that by understanding their patients; providers can connect to their patients (Stein 2009). Providers attempt to do this through cultural competency. Cultural competency

refer[s] to a body of knowledge, skills, attitudes, and behavior in which physicians ought to be trained if they are to deliver "sensitive," "empathetic," "humanistic" care that is "respectful" of patients, involves effective "patient-centered communication," and responds to patients' "psychosocial issues and needs" (Fox 2005).

Unfortunately, many providers and medical schools view cultural competency as a list of “dos and don’ts” that correlate with a particular population (Betancourt 2004). This view of cultural competency is wrong because “the idea of isolated societies with shared cultural meanings would be rejected by anthropologists, today, since it leads to dangerous stereotyping (Kleinman & Benson 2006). Understanding a cultural belief is important but a “one-size fits all” approach is ineffective. For example, many providers believe that patients with strong religious beliefs are more likely to be adherent. Yet, some patients believe that a higher power gave HIV to them and these patients accept their fate and do not take their ARVs (Kremer et al. 2009). In addition, many providers do not understand the self-reflexive nature that cultural competency requires. Many view the biomedical system as devoid of culture (Fox 2005, Kleinman & Benson 2006, and Taylor 2003). Without understanding how the providers and their medical culture affect the patients, the providers cannot truly understand the patients.

Thus, a useful method to understand a patient’s perspective is the use of an explanatory model approach (Kleinman & Benson 2006). An explanatory model allows the patient to make sense of his/her illness and how he/she experiences that illness (Kleinman 1978, and Kleinman 1988). The provider can communicate with the patient using the language of the patient and the provider can understand the patient’s own illness narrative (Kleinman 1988, and Kleinman & Benson 2006). Previous research shows that the use of patient illness narratives can be effective in understanding aspects of HIV medication adherence and in increasing adherence itself (Wrubel et al. 2011, Scott 2009, and Sankar et al. 2011). Some of the patients’ definitions of adherence can be quite different than their providers. For example, a patient can change the dosing of his/her ARV without consulting his/her clinician. While a provider would consider this patient noncompliant, this type of patient may feel that he/she was adherent to the medication because he/she still took them (Hill et al. 2003).

Understanding the explanatory models of patients includes aspects such as whether or not the patients believe in the efficacy of HAART and if they understand how the medications work (Chesney 2003). Providers also need to comprehend the definitions and language of their patients. Simply recalling information does not guarantee adherence, especially when that information is not understood (Hunt et al. 1989). Living with HIV is a personally experienced illness in which the meaning of the disease can be different for each patient (Scott 2009). For example, some patients view their status as a form of punishment for past behaviors (Scott 2009). Some patients perceive their bodies as frail while others view their bodies as strong and able to “withstand” HIV without medications (Hill et al. 2003). Other patients can become confused in regards to the importance of adherence. Adding to this confusion, sometimes providers place patients on structured treatment interruptions (STIs), after harping on the importance of adherence for months. This conflicting information can confuse patients about the importance of adherence (Adam et al. 2003).

Adhering to any type of medication, not just an ARV, is difficult and barriers often develop. Additionally, therapies for chronic conditions are harder to adhere to over time. Patients who suffer from chronic conditions, like HIV, have to make their medications a part of their daily lives and adhere to the treatment for the rest of their lives (Polaschek 2003). These patients may need assistance in increasing their personal care goals and self-efficacy to manage their disease. This means that patients must be educated about their health issues and empowered to take control of their medications (Jerant et al. 2005).

Studies show that it is difficult for people to adhere to simple regimens that only require one pill to be taken once a day (Osterberg & Blaschke 2005). Unlike many other regimens, HIV medication regimens have a high pill burden. Most of the HIV medication regimens prescribed to the patients in this study required the patients to take two to three different medications. Many of these regimens consisted of multiple pills that were prescribed at different times of the day.

Although there are improvements in simplifying these regimens, HIV medications continue to be one of the most difficult regimens for patients to adhere to (Osterberg & Blaschke 2005).

While a number of internal and external factors that create barriers to adherence exist, ultimately it is the tolerability of the medications that plays the most significant role in determining adherence (Hawkins 2010). If a patient cannot tolerate the medication and its adverse effects, it is likely that the patient will have difficulty adhering to the therapy.

Side Effects and Medication Toxicity:

All medications have some type of adverse effects or side effects, which are the unintended physiological reactions a person has to a given medication. Some side effects are mild and may dissipate after taking the medication for a few weeks. Other side effects can persist for as long as the patient is taking the medication (Remien et al. 2003). The experience of side effects is an individualized phenomenon. There are varying degrees of these effects and patients may conceptualize the side effects differently. Scientifically, side effects are the secondary reactions to the medication, while the primary reaction treats the intended illness. Yet, a patient's beliefs about side effects can be culturally based. Vomiting and diarrhea, while considered side effects to the medical community, some cultures view as part of the natural healing process (Etkin 1992).

Unfortunately, it is the long-term side effects that many HIV+ patients suffer. Some of these side effects are so serious that they can make patients feel sicker than the virus alone does. Patients must determine how they feel about their medications and if they are to manage the side effects. Some patients learn to deal with the side effects (Shoemaker & Ramalho de Oliveira 2008). While others refuse to take a medication that makes them feel sicker (Adam et al. 2003), other patients feel that the medications take control over their lives

(Dolovich et al. 2008). Some patients become complacent with the side effects because the side effects may kill them faster than the disease (Shoemaker & Ramalho de Oliveira 2008). Understanding patients' personal and cultural beliefs on side effects is important to aid in adherence because without this understanding, providers may be unable to conceptualize what it is like for their patients to experience these side effects.

One of the most serious types of side effects is medication toxicity (Chesney 2003). This occurs when a medication is too strong for the body and becomes toxic, causing the patient to develop additional, and sometimes deadly, health problems. The patient is dependent upon the medication to fight the virus to maintain his/her health. Because of the medication's toxicity, if the patient continues to take the medication everyday, he/she will become sicker. Medication toxicity typically does not dissipate over time (Clifford et al. 2009). While adherence to ARVs is difficult, a HIV+ patient who develops toxic reactions from his/her medication now suffers from multiple life-threatening conditions.

Little is known about the long-term effects that HAART has on the aging body because HIV medications are relatively new (Max & Sherer 2000, McPhail & Robertson 2011, Palmisano & Villa 2011). Unless a cure is found, HIV+ patients will rely on these medications for the rest of their lives. It is difficult to predict what types of reactions their bodies will have to these medications when taken for a prolonged period of time. Even less is known about the long-term effects caused by ARV toxicity because clinical studies are typically not long enough to capture this information (Hawkins 2010). Sadly, many believe that investing time and money in understand the long-term effects of the current HIV medications is not cost-effective since, due to the highly mutative nature of the virus, patients are in constant need of new medications to repress viral replication.

Medication toxicity is a unique factor for studying adherence. Every patient's body is different, and because of pharmacogenetic variability (biological

individualism) there is no way to predict how a patient will respond to a medication or what the side effects will be (Cressey & Lallemand 2007). While guidelines for the prescribing and dosing of these medications exist, ultimately, a provider needs to know his/her patients and watch how each individual reacts to the medications. To do this, a provider must develop rapport with his/her patients. Trust and honesty are necessary in the patient-provider relationship. The doctor needs to ask tough questions that deal with the personal factors that affect adherence like alcohol and drug use, physiological and emotional health, and personal feelings about health and therapy. The patient also needs to feel comfortable answering these questions truthfully. Only with complete honesty will the doctor understand how the medication affects the patient and gauge what types of adherence barriers need to be addressed.

It can be difficult for patients and providers to have these necessary conversations. The social, physical, emotional, and psychological aspects of living with HIV are extremely personal, and such conversations delve into the intimate parts of peoples' lives. Moreover, studies show that such conversations between patients and providers are typically awkward (Barfod et al. 2006). It can be hard for patients to open up and be honest with their doctors because the doctors are the ones with the power in the relationship (Osterberg & Blaschke 2005). The clinicians control whether or not the patients can receive therapy, and many patients just want to tell the doctors what the doctors want to hear (Osterberg & Blaschke 2005). It is not uncommon for doctors to judge their patients (Trostle 1988), and not address the social stigma associated with having HIV and this can emotionally affect patients (Rintamakami et al. 2006).

Renal Toxicity:

Toxicity is a serious concern when using HAART, and some forms of medication toxicity are fatal. One of the newest forms of HAART associated with toxicity involves particular HIV medications that affect a patient's kidneys. In fact, regardless of renal toxicity, a correlation between HIV and kidney problems

already exists. Due to the nature of HIV, and the way it compromises the immune system, many HIV+ patients already have renal problems (Post et al. 2008). Kidney disease is the third leading cause of death in HIV+ patients (Santos, Seguro, & Andrade 2010), and 30% of HIV+ patients have abnormal kidney function (Singer 2009). In fact, when renal problems develop, over a third of the time, US doctors immediately check to see if the patient contracted HIV (Rao 2001). The virus not only infects CD4-cells but also compromises cells in the kidneys causing renal problems and can ultimately cause renal failure.

Renal toxicity is a major threat to patients' health, and some medications (including several HIV medications) are nephrotoxic. By taking these medications patients may experience a side effect in which their medications causes additional problems with the kidneys and may ultimately cause kidney failure, which can be fatal (Roling et al. 2006 and Daugas, Rougier, & Hill 2005). Due to the limited number of HIV medications, pharmacogenetic variability, and drug-resistant strains of HIV, patients require these medications even though the medications may eventually harm the patients. Statistically, most patients never develop these fatal renal problems, so their best chance at survival is taking these potentially harmful medications (Post et al. 2008). HIV+ patients that develop renal side effects from their HIV medications must undergo dialysis treatment in order to continue their necessary ARV treatments.

Some of the nephrotoxic medications are excreted through the kidneys. If left in the body these medications would become even more toxic and would kill the patient. The provider and patient face a puzzling dilemma. If the patient were to stop taking the medication, the virus would mutate, rendering the medication ineffective and HIV would replicate throughout the bloodstream eventually compromising the patient's immune system, leading to death. Yet, if the patient continues to take his/her medication every day, as prescribed, the kidneys could not flush the medication out of the body thus making the medication toxic, killing the patient. Due to this predicament, doctors, pharmacists, drug companies, and

researchers advise providers to change the dosage of the medication and follow specific guidelines called renal dosing.

Renal dosing itself is not new and is used on a variety of medications. Since the kidneys cannot excrete the medication out of the body, placing more medication in the body becomes dangerous. The doctor changes how often the patient takes the medication so that the medication can still be effective, while not becoming overly toxic. The protocol for renal dosing is different for each medication, but for most of the HIV medications that are still used today, the doctor instructs the patient to take the medication only after dialysis treatment, which is typically once or twice a week. By following this strategy, the body takes in the medication and that single dose will remain in the body to combat HIV until the next dialysis treatment. The dialysis treatment removes the medication from the body; thus, another dose of the medication is needed. While renal dosing is not perfect in combating the virus, pharmaceutical research show that it is effective in keeping HIV from destroying the patient's immune system (Gilead: Pharmaceutical Manufacturer, Highlights of prescribing information).

While providers utilized renal dosing strategies since the 1950s, the renal dosing of HIV medications is still relatively new in the medical world. It was not until the early 2000s, that the medical community discovered the need for renal dosing in HAART. Until a few years ago, all of the literature stated that HIV medications could only be effective if taken every day. The addition of renal dosing greatly changed the way in which providers prescribe HAART. Even with the number of adherence interventions, noncompliance with HIV medications continues to be a major issue for patients placed on renal dosing (Santos, Seguro, & Andrade 2010). Although mortality rates for HIV+ patients decreased over the years, mortality rates for HIV+ patients with renal problems remains high (Rodriguez 2003).

Tenofovir and Toxicity:

Over the years the medical community identified various nephrotoxic medications and replaced many with newer and safer medications. This thesis focuses on one recently identified nephrotoxic ARV called Tenofovir, also known by its brand name: Viread (Bruggeman, Bark, & Kalayjan 2009, Kearney et al. 2004).

Tenofovir is an HIV medication in the class of nucleotide reverse transcriptase inhibitors (NRTIs). NRTIs work by preventing HIV from changing the genetic coding of CD-4 cells, stopping the cell from making new copies of the virus.

Tenofovir is a newer medication and the FDA approved it in 2001 (FDA: Antiretroviral drugs used in the treatment of HIV infection). The medication is a successor to previous medications that patients found less tolerable. A single dose of Tenofovir, once a day, is effective to stop HIV replication, making it a very popular medication in drug regimens. Tenofovir is also an active ingredient in many of the combination medications that combine multiple HIV medications into one pill.

While Tenofovir is extremely effective in combating HIV, studies show that the medication can cause renal problems (Gallant & Moore 2009, Karras et al. 2003, Schaaf et al. 2003, Zimmerman et al. 2006). The pharmacogenetic variability of the medication is diverse. Patients react differently to the medication and there is no way to predict if renal toxicity will occur. After years of testing and years on the market, the initial data did not show any correlation between the medication and renal problems. As the years passed studies began to reveal that Tenofovir caused renal problems. An explanation for the lack of initial data is that prolonged use of the medication increases the likelihood of renal issues (Rosso, Ginocchio, & Bassetti 2008, Coca & Perazella 2002). While there is some literature on these adverse events, the literature is still scarce. At the present time only 2% of the HIV population in the United States suffer from renal problems caused by Tenofovir (Hamzah & Post 2009). While this may not appear to be a major medical concern, some researchers and doctors believe that the incidence of renal dosing will greatly increase in the next few years

(Wanner, Tyndall, & Walker 2009). The popularity of the medication (Shepp, Curtis, & Rooney 2007), combined with prolonged use, may result in an increase of renal problems.

With both limited kidney function and compromised immune systems, it is extremely important that HIV+ patients with renal complications adhere to their medication regimen even while they are on renal dosing. If the virus is uncontrollable it can cause serious health problems for patients with a compromised renal system. Even with the adverse problems associated with the medication, HAART therapy is still effective in patients undergoing dialysis (Ahuja, Borucki, & Grady 2000). While adherence for this group of people is extremely important, almost no research is conducted with them. This is probably because renal dosing of HIV medications is still new to the field. This makes renal dosing a factor in adherence that deserves further research. Understanding drug toxicity and the barriers it presents is important in determining whether patients will adhere to their medication regimens (Szczech et al. 2002).

While adherence is an issue for all HIV+ patients, those on renal dosing have additional issues that need addressing. There is no set standard of renal dosing for providers to follow. While the drug companies supply guidelines, patients are unique and the medication may react differently with each patient, making the dosing dependent on the level of renal problems each patient has (Kearney et al. 2004). This means that providers must be attentive to patients who have renal issues and take these renal problems into account when prescribing medications (Papaioannou et al. 2000).

Due to the large number of patients it can be difficult for providers to keep up to date on all of their patients. Unfortunately, some medications are incorrectly prescribed to patients (Rodriguez 2003), and some studies suggest that many of the nephrotoxic medications are overprescribed (Papaioannou et al. 2000). In

addition, some HIV+ patients do not receive adequate dosing of their medications to suppress the virus (Szczech et al. 2003). This variability in the recommended dosing makes it difficult for providers to prescribe the right dosing for their patients. Ultimately, prescribing can become a trial and error method. In situations like this, good rapport with patients is again vital for the patient-provider relationship. Doctors need to understand patients' lived experiences and the patients need to trust their doctors. Without a good working rapport, this is nearly impossible (Tourret et al. 2007).

There is an added burden on the patient-provider relationship for renal dosed patients. Two of the groups that renal dosing affects the most are African Americans (AA) and Intravenous Drug Users (IDUs), who often have poor rapport with providers (Bogart et al. 2010). This places even more demand on providers to strengthen their relationships with these patients because incorrect dosing can lead to increased toxicity and adverse events, which, in turn, can decrease adherence and cause drug resistance (Willig et al. 2007).

Even when providers find the correct dosing, human error can still occur. In a number of hospital studies, doctors and nurses made errors in the dosing of this medication. The doctors and nurses administered suboptimal therapy (Ahuja, Grady, & Khan 2002), which led to complications that resulted in decreased survival rates (Tourret et al. 2007). Patients not receiving the correct dose of the medication was the cause of some these errors, but patients not receiving the medications at the correct time was the cause of most of the errors (Tourret et al. 2007). For patients on renal dosing, there is a specific time frame within which the medications should be administered, and many of the hospital workers did not give the medications to the patients in accordance with these guidelines (Tourret et al. 2007).

If patients receive suboptimal therapy in the hospitals, where trained professionals administer the medications, then adherence in the home, where

patients take their own medications, must be a high priority and should be studied more. Many renal dosing patients travel to a dialysis center. Since the patients travel, the patients need to remember to bring their medications with them and take the medications at the proper time. Although there are health care professionals at the dialysis centers, these professionals are not the HIV care providers. Thus, the HIV clinicians do not know whether their patients are taking the medications at the proper times.

HIV medication regimens have a high pill burden and it is difficult for patients to adhere to them (Wensing, van Maarseveen, & Nijhuis 2010). HIV regimens usually include multiple medications that must be taken every day. Patients on renal dosing have a higher pill burden than other HIV+ patients. Renal dosing patients must remember to take some of their medications every day as originally prescribed, and the renal dosing medications only after dialysis. It can be challenging for HIV+ patients to remember to take their pills every day. Changing patients' regimens to renal dosing greatly increases the chances of noncompliance because patients must remember to take some of their medications everyday and other medications only a few times a week. This is difficult for patients who were on their medications for a prolonged period of time and developed pill-taking habits.

Renal dosing patients, like many other HIV+ patients, suffer from comorbidity, the presence of two or more diseases. Managing one disease is difficult, but managing multiple diseases is extremely problematic (Bayliss, Ellis, & Steiner 2007). Comorbidity in HIV+ patients increases the likelihood of opportunistic infections and a compromised immune system (Ahuja, Grady, & Khan 2002). Patients must adhere to therapy for all of their illnesses because if they are noncompliant with a therapy their health can deteriorate. Patients who have multiple chronic conditions have increased health burdens. By increasing patients' self-efficacy and agency, providers can assist in the adherence to medication therapies.

While these factors affect a number of HIV+ patients with comorbidity, renal patients have additional factors. Due to the unique dosing regimen of this group, and the pharmacogenetic variability of the medications, the medications may not be potent enough to be effective. Even when patients are adherent to their regimen, there is no guarantee that the medications will be effective (Cressey & Lallemand 2007). This can become frustrating for patients and the providers, and typically both find something or someone to blame (Maskovsky 2005). In situations such as this the providers may place the blame on the patient, while the patients may place the blame on the therapies (Rousse 2010). In scenarios such as this, the chances of adherence are greatly reduced because the rapport between provider and patient is lost (Seema et al. 2011, and Beck & Gordon 2010).

The therapies used to treat HIV+ patients on renal dosing are complicated and the adverse effects can cause additional health problems for the patient (Singer 2009). Adverse effects like drug toxicity greatly interfere with the daily routines of patients, which, in turn, can affect adherence (Remien et al. 2003). Patients need to believe that the medications are helping them even when the side effects are detrimental to their health. If patients believe the medications are hurting them, complications usually arise in adherence (Remien et al. 2003).

Patients on renal dosing receive at least two types of therapy for their chronic conditions. They receive HAART for their HIV and dialysis for their kidney problems. It is hard for some patients to trust in either of their therapies because the therapies can become iatrogenic syndemic. Iatrogenic syndemics occur when the healing therapies used to treat conditions in a comorbid patient cause adverse effects that make the disease not treated by the medication worse (Singer 2009). For renal-affected HIV+ patients, taking nephrotoxic HIV medications stops HIV replication but causes kidney damage or failure. Some studies show that dialysis treatments can make HIV replicate at a faster rate

(Ahuja, Grady, & Khan 2002). Thus, undergoing dialysis treatments allows patients to excrete the toxic waste from their bodies but may cause faster virus replication. Patients must adhere to both therapies for survival, yet each therapy can make the other condition worse. This makes the patients even more reliant on the treatment, which in turn can cause the conditions to worsen. Noncompliance for those who are on ARV and dialysis treatments is common (as cited by Curtin, RB et al. 1999, Leggat, JE et al. 1998, and Kimmel, PL et al. 1995 in Loghman-Adham 2003), and this cycle may make it worse.

Review:

In sum, adherence to an antiretroviral (ARV) medication regimen is necessary for seropositive individuals to survive. Due to the vast number of factors and difficulties people experience from living with HIV, barriers to medication adherence develop. Understanding these barriers and helping HIV+ people overcome them can greatly increase rates of adherence. However, little research is conducted on the barriers to adherence for people living with HIV that providers place on a renal dosing ARV medication regimen. In addition, this population experiences unique conditions in living with HIV. This can result in specific barriers to adherence for population. Thus, more research needs to be conducted on adherence and the barriers to adherence for this population.

LifeWindows Project Background:

The LifeWindows project (Fisher et al. 2011) is a psychological research study headed by Dr. Jeffrey Fisher, head of the University of Connecticut's Center for Health, Intervention, and Prevention (CHIP). I worked for Dr. Fisher as a researcher on this project. The team developed the survey instrument and protocols for the study prior to my arrival. My roles as a researcher included: the testing of the computer program, participant recruitment, participant retention, working with patients, running participants through the LifeWindows program,

and administrative duties. Dr. Fisher and the research team gave consent for use of project data for this thesis.

The team conducted the study at five HIV clinics located throughout the state of Connecticut. PhDs, administrative and support staff, and an on site researcher for each of the HIV clinics comprised the LifeWindows Project team. This was a voluntary study and all participants gave written, informed consent to participate in the research. The Institutional Review Boards (IRB) at the University of Connecticut and at each of the HIV clinics approved this research.

LifeWindows Computer Program:

LifeWindows is an interactive computer based ARV adherence support intervention. The computer program worked with HIV+ patients based on the IMB model of adherence in order to assess patient adherence, identify barriers to adherence, and test the efficacy of specific adherence interventions.

As previously discussed, the IMB model of adherence works on the premise that information, motivation, and behavioral skills are critical factors that affect adherence and those patients that possess these skills can apply them to their ARV regimen. The IMB model also suggests that identifying the barriers to these skills and addressing them can increase patients' adherence. The study included both a control arm and an intervention arm. Participants in both arms used the LifeWindows computer program, but only those patients in the intervention arm had exposure to the adherence interventions.

The computer program consisted of several components. The first component was a tutorial that explained basic computer usage and how to use the LifeWindows program. Each time a patient entered the program Marcus, a virtual guide, greeted the participant, introduced him/her to LifeWindows and helped him/her navigate through the computer program.

After Marcus's greeting, the patient completed a general assessment module. The first part of this module elicited background information and demographic characteristics (these survey questions are in Table 7 located in the Appendix) by allowing the patient to choose from a list of provided responses. The patient completed the survey by using the mouse to click on the responses. Due to the nature of these questions, the responses ranged from binomial (yes/no) responses (e.g., Are you currently taking a break from your HIV medications without talking to your healthcare provider?) to questions that provided over 20 responses to choose from (e.g., In what year were you diagnosed with HIV?). Also, some of the questions asked for a single response while others asked for all responses that applied (e.g., How did you first get HIV?) During the baseline session of LifeWindows the patient completed the entire survey. On subsequent sessions the patient only responded to questions about things that could have changed since the last visit. The patient could also choose "Prefer not to answer" for all of the questions.

The second part of the module was a survey of possible barriers to adherence (the survey questions are in Table 8 located in the Appendix). Like the demographic survey, this part of the module showed the patient responses for each question. Also like the previous survey, the number of responses was not uniform. Many of the questions' responses were Likert scales. The survey looked for barriers to adherence based on the IMB model. Thus, questions asked focused on the patient's informational, motivational, and behavioral skills. The patient had the option to choose "Prefer not to answer" for all of the questions.

The final portion of this module was an interactive survey to assess ARV adherence. The module started with a section called the "Pill Picker." In this section the patient chose all of the HIV medications that he/she was prescribed. To help the patient choose the correct medications, the program showed pictures of each ARV medication. The list included both brand and generic medications

that were in use during the time of the study. Also the patient could sort the list by the medications' name, size and shape, or function.

Prior to the patient's session of LifeWindows, the site researcher would examine the patient's medical chart and update the program's database with the current ARV medications. During the "Pill Picker" section, if the patient failed to choose the correct medication or chose a medication that was not in the database, the program took the patient to the "Discrepancy" section. In this section the computer showed the patient which medications were listed in the database and which medications he/she chose. The patient then choose the medications that he/she believed he/she was on, which would override the discrepancy if necessary, but would create a report for the team to examine at a later time. When completed, or if no discrepancy existed, the system brought the patient to the adherence survey.

The adherence survey asked the patient to report on his/her adherence over the last three days and over the last four weeks. The system displayed a daily calendar for each of the ARV medications. Then the program asked the patient to choose the times during the day and the number of pills prescribed for each HIV medication. The program asked the patient to report whether he/she took each medication over the last three days and how many pills he/she took at that time. The patient reported his/her adherence in the form of a percentage with 0% signifying that he/she took no medications, to 100%, which signified that he/she took all medications as prescribed. The computer asked the patient to report on each medication for the past three days and then for the past four weeks.

This was the end of the program for those patients in the control arm of the experiment. The patients in the intervention arm went on to receive an adherence support component that had 20 different individually targeted intervention activities. The patients interacted and completed the activities on the computer.

The activities included things such as: an informational movie, asking experts specific questions, a computer game, receiving relevant information, and a variety of other activities (the listing and description of the intervention modules are in Table 9, located in Appendix). The computer program kept a record of the survey questions that positively identified possible barriers to adherence from the general assessment. Each of these questions linked to a particular adherence strategy (a list of these strategies is in Table 10 located in the appendix). After completing the general assessment the patients in the intervention arm chose from a list of adherence strategies that they could work on while in LifeWindows. The strategies linked to the survey questions that identified a possible barrier to adherence. After choosing a strategy, the patients chose which interventions they wanted to complete. The patients selected the intervention they wanted to work on and engaged in the activity. Each of these interventions addressed specific adherence strategies. The purposes of these interventions were to increase patients' information about HIV and HAART, increase patients' motivation about taking medication, and change patients' behavioral skills in taking medications. Table 11 (located in the appendix) shows which strategies and interventions linked to each question.

After completing the interactive activity the patient went to a goal selection module. In this module the patient chose an adherence related goal. The program presented some already prepared goals on the screen. These goals focused on the patient's self-identified barriers to adherence and the intervention the patient completed. The patient could also create a personal goal. The system printed the goal and presented it to the patient. On subsequent visits Marcus asked the patient about his/her progress on the goal.

The LifeWindows session concluded with a farewell message from Marcus, reminding the patient to return to LifeWindows during the next doctor visit. On the final LifeWindows session, or exit survey, Marcus thanked the patient for his/her help in the study.

LifeWindows Survey Questions:

As previously discussed, the LifeWindows computer program consisted of three different computer delivered surveys: demographic information, adherence barrier identification, and adherence to HAART medication regimen. The data used in this thesis focuses mainly on the adherence barrier identification survey. The LifeWindows research team developed these questions to identify possible barriers to adherence that affected participants in the study. Nearly all of the responses to the questions were Likert scales. Each time the patients participated in a LifeWindows session, the program asked the same 45 questions. Of the 45 questions, only 34 linked to an adherence strategy. The remaining questions still identified barriers to adherence, but did not affect the LifeWindows session.

Barriers Identified in LifeWindows:

The questions, responses, strategies, and interventions identified in this thesis all came directly from the LifeWindows program, and the LifeWindows team developed them using the IMB model of adherence, research from previous studies, and consultations with HIV clinicians. While the general assessment identified barriers to adherence, the research team did not name each specific barrier. For this thesis I created the names for the barriers to adherence based on each survey question and its linked adherence strategy. The full list of barriers addressed through the strategies and interventions are in Table 12 located in the appendix.

The LifeWindows program identified a total of 37 barriers, based on the IMB model of adherence. Since there were 45 survey questions and 34 adherence strategies, some of the barriers correlated with multiple questions. The research team developed these questions because they believed that barriers could exist for people in a variety of ways. Developing the questions in this manner allowed

the team to identify more barriers to adherence, and with these barriers the program routed the patient to the appropriate intervention.

LifeWindows Results:

The LifeWindows study tested the hypothesis that those patients exposed to the interventions would have greater adherence over time than those patients in the control arm, because the interventions better addressed the barriers to adherence than the patients' previous exposure. The purpose of this study was to test the hypothesis and, if proven, to determine which interventions most improved patients' adherence. The study found that the intervention significantly improved adherence (Fisher et al. 2011).

Participants for this Thesis:

The team recruited 590 participants for the LifeWindows study. The criteria for inclusion into the study were that each participant had to be: HIV+, a patient of the clinic, 18 years of age or older, on ARV therapy at baseline, and competent in the English language at a fourth grade reading level. Recruitment occurred at all five of the HIV clinics. Each clinic had affiliations with its own hospital and its location was within or next to the given hospital. Four of the five hospitals were cities in poor neighborhoods in the state. Most of the participants were minorities from a lower socio-economic status.

Nurses, physician assistants, and doctors staffed the clinics. The number of times patients frequented the clinic depended on their physical health. Patients who were not healthy and whose viral load was high came in every month; patients who were in good health only came in every three months; and patients who were in excellent health and who had an undetectable viral load came in every six months. The frequency of visits was one of the few characteristics that differed between the sites. Patients who were in better health and who visited the clinic less often came mostly from the one clinic located in the suburb. The

only other notable difference was that the clinic located in the suburb had a higher socio-economic population.

The clinicians referred all participants to the team and the participants freely chose whether they wanted to take part in the study. Each on-site researcher randomly assigned his/her participants into either the control or intervention conditions. After recruitment, the patients completed informed consent procedures and baseline measures by participating in their first LifeWindows session.

The participants interacted with LifeWindows for approximately 18 months between March 2006 and March 2008 in a private location in the HIV clinic prior to seeing their provider for routine HIV medical visits. Patients could complete up to one LifeWindows session a month and received \$20 for each session they completed.

Of the 590 patients recruited in the study, 12 had their regimen changed to renal dosing during the study period. Throughout this thesis the group of individuals placed on renal dosing is the renal dosing group (or RD), while the entire sample population is SP.

Similarities between the Sample Population and Renal Dosing Group:

Most of the demographics and characteristics of the RD were similar to the SP. Throughout both populations in the study there were slightly more male than female patients (SP= 61.2% male, RD= 58.3% male). Most of the population identified themselves as heterosexual (SP= 74.1% and RD= 83.3%). There was a slight difference between the groups among those who did not identify themselves as heterosexual. In the total sample 19.2% of the population identified themselves as homosexual and 6.7% identified themselves as bisexual. In the renal sample only 8.3% identified themselves as homosexual

and another 8.3% identified themselves as bisexual. Also, most patients had few to no children (SP= 1.17 children, RD= 0.3 children).

Most of patients in the study lived with HIV for more than ten years (SP= 13.25 years, RD= 14.18 years). While this is not a significant difference there is a chance that the years lived with HIV may be correlated with being on renal dosing. Since long-term use of Tenofovir can cause kidney problems, the longer a patient takes the medication the more likely he/she is to develop renal issues. Due to the small sample size of RD this thesis cannot test this hypothesis, but this may warrant future testing.

The most significant characteristic that the two groups shared was their living situation. The vast majority of the populations lived in stable housing (SP= 90.9%, RD= 91.6%). The living situations of the patients did not appear to be a factor that affected adherence, yet very few patients had employment (SP= 39.3%, RD= 25%). This characteristic greatly affects the socio-economic status of the patients and can impact their adherence. On average, the patients in the study lived close to or below the poverty line (SP= \$17,219 a year, RD= less than \$10,000 a year). I expected this result because those patients on renal dosing would work less and make less money than other patients due to the physical problems and limitations that kidney failure causes. It is important to note that this survey question asked about family income and there was no way to determine if participants included other sources of income (such as welfare or supplemental security income) when they answered this question. This data show that income is a characteristic correlated with RD and may be a barrier to adherence. Income may also be a barrier for SP since less than 40% of the patients in the study found employment.

Differences between the Renal Dosing group and the Sample Population:

While the two groups shared many characteristics there a number of characteristics differed. The most notable of these was race/ethnicity. Most

patients in the study were minorities. For both samples African American (AA) or Black was the largest ethnic group that patients identified. The sample population was 44.1% Black, while the renal dosing group was 66.6% Black. Although this is a significant difference, the difference in the sample sizes may skew the findings. It is interesting to note that in the general population kidney problems concentrate among those who are Black (Bogart et al. 2010).

While many patients in both samples contracted the virus through heterosexual intercourse (SP= 39.1%, RD= 41.6%), the groups differed on the other ways the patients contracted the virus. The largest difference was for those who contracted HIV due to intravenous drug use (SP= 21/2%, RD= 41.6%). While the size of the sample may skew the findings, this is also interesting because like being AA, IDUs are also more likely to develop kidney issues than non-IDUs in the general population (Bogart et al. 2010). These characteristics and further information are below in Table 1.

Table 1: Demographic Information and Characteristics

Characteristic	Total Sample Population	Renal Dosing Group
Male	361 (61.2%)	7 (58.3%)
Female	229 (38.8%)	5 (41.6%)
Years with HIV	13.25	14.18
Number of children	1.17	0.3
Heterosexual	431 (74.1%)	10 (83.3%)
Homosexual	112 (19.2%)	1 (8.3%)
Bisexual	39 (6.7%)	1 (8.3%)
Living in stable housing	538 (90.9%)	11 (91.6%)
Black/ African American	262 (44.1%)	8 (66.6%)
Latino/a	151 (25.4%)	1 (8.3%)
White	141 (23.7%)	3 (25.0%)
Other	40 (6.7%)	0 (0.0%)
Employed	233 (39.3%)	3 (25.0%)
Yearly income	\$17,219	Under \$10,000
HIV infection: MSM	85 (14.3%)	2 (16.6%)
HIV infection: Heterosexual sex	232 (39.1%)	5 (41.6%)
HIV infection: IDU	126 (21.2%)	5 (41.6%)
HIV infection: Blood transfusion	15 (2.5%)	0 (0.0%)
HIV infection: Multiple ways	54 (9.1%)	2 (16.6%)
HIV infection: Unknown	73 (12.3%)	2 (16.6%)
HIV infection: Refused to answer	6 (1.0%)	0
HIV infection: Sex but gender unknown	2 (0.3%)	0 (0.0%)

Data courtesy of the LifeWindows Project Team 2006

Data:

The LifeWindows project tested the hypothesis that by exposing HIV+ patients to interventions that addressed barriers to adherence the patients' adherence rates would increase. Prior to the study, the literature and conversations with providers, all stated that patients must take their ARV medications every day at the same time in order for the medications to be effective. The team designed

the computer system and study in this manner to measure adherence by tracking whether or not patients took the prescribed dose of each medication every day.

During the study providers changed the ARV regimen of several of their patients. Among these were 12 patients that the clinicians placed on renal dosing. These patients suffered from kidney problems that required dialysis. Since the body excretes these HIV medications through the kidneys, the providers changed these medications before they became toxic for these 12 patients. The providers changed the dosing for these medications from once every day to once or twice a week following a dialysis treatment.

Since the design of the LifeWindows computer program only tracked adherence on ARV medications taken every day, the automated program for adherence could not assess adherence for these 12 patients. While adherence was not tracked, the automated program captured the barriers to adherence that these patients positively identified. My thesis examines these barriers to adherence to see if any of them are unique to this population and to better understand the lives of these patients to help increase adherence rates for HIV+ patients placed on renal dosing.

Examining the Data:

The examination of the case notes made by the site researchers identified the renal dosing patients in the study. This examination yielded 12 patients placed on renal dosing during the study. These 12 patients hereafter are the renal dosing group and the rest of the sample is the normal dosing group.

As previously discussed, each time a patient completed a session of LifeWindows he/she answered 45 survey questions that identified 37 possible barriers to adherence. The responses for these 45 questions ranged from two to six options (with an additional response of “refuse to answer” for each question). For the analysis of this thesis, I coded the responses binomially for uniformity. If

the response did not identify a barrier or if the patient chose “refuse to answer” the coded response was a 0. Since “refuse to answer” did not identify a barrier, coding as a 0 omitted this response from the data set. This coding scheme is useful in survey research because refusal to answer is usually unrepresentative of a sample and does not change data set (Kent 2001). If the response identified a barrier the coded response was a 1. These criteria were the same as those used in the LifeWindows adherence algorithm that identified which intervention strategies the LifeWindows program showed the patients.

The patients’ responses were then sorted chronologically by each LifeWindows session they completed. For this thesis I only used the baseline and final survey responses to identify and analyze the barriers to adherence. These two time frames best compare the responses of patients in each of the dosing groups. Since all patients entered the study while on normal ARV therapy dosing, the renal dosing group did not exist at baseline. Those patients placed on renal dosing remained on a renal dosed regimen throughout the remainder of the study. The final survey clearly divided the normal dosed patients from the renal dosed patients. The final survey responses also reflect longer lasting barriers to adherence because the patients had months to acclimate with the change in their medication regimen.

Thus, patients had to complete at least two sessions of LifeWindows to be in the samples for this thesis. This thesis does not include data from patients who only completed a baseline survey. The thesis also does not include data from patients who failed to answer all of the questions during the baseline or final surveys. This provides an accurate range to detect the barriers identified by patients. The final sample included 12 patients in the renal dosing group and 513 patients in the normal dosing group. While the total sample had 590 participants, due to attrition or lack of answering all questions, only 513 participants remained in the normal dosing group in this analysis.

Data Analysis:

The analysis of the data used the SPSS statistical software package. The analysis used Paired Sample T-Tests, Independent T-Tests, and Chi Squared tests to examine whether there were significance differences between the two groups and to identify significant barriers to adherence.

Results:

I analyzed the data to see if there were specific barriers to adherence that only the patients on renal dosing identified as a barrier. I hypothesized that the switch to a renal dosed regimen would increase the barriers and difficulties patients had in adhering to their ARV medications. In this analysis I examined the overall number of barriers identified by the patients and looked at each survey question to determine if it disproportionately affected those patients on renal dosing. When I found barriers that greatly affected the renal group, I then examined these barriers further to better understand them and offer recommendations on how to help this population increase adherence.

Based on the 45 questions from the LifeWindows survey, each patient identified between 0 and 45 questions that positively correlated with a barrier to their ARV adherence. The total number of questions that positively identified barriers to adherence for the renal group's responses compared the group's baseline and exit surveys. A Paired Sample T-Test found an average of 18.25 questions that positively identified barriers on the baseline surveys and an average of 14.58 questions on the exit surveys. There was no correlation or significance found in these results. Thus, being placed on renal dosing did not increase the likelihood that a patient would experience more barriers to adherence. This decrease in barriers may be a result of exposure to the intervention arm of the study, but this is unlikely. There is no indication that the reduction for renal dosed patients was a result of exposure to the intervention arm. Like the general sample population, about half of the patients in the renal group happened to be placed in the

intervention arm of the study. Of the 12 participants, five were in the intervention arm and 7 were in the control arm.

For the analysis I used an Independent T-Test to compare the total number of questions that positively identified adherence barriers at baseline between the two groups. This analysis showed that at baseline, on average, the total number of questions that identified barriers was 18.25 for the renal sample and 15.64 for the normal dosing group. Again the analysis did not find any correlation or significance. I expected this result because at baseline, none of the providers placed their patients on renal dosing, thus the two groups had the same number of barriers.

The analysis also ran an Independent T-Test on the exit surveys, which compared the same total number of questions between the two groups. This analysis showed that at the completion of the study the two groups had, on average, almost the same number of questions. The renal group averaged 14.58 and the sample group averaged 15.41. Again, the analysis did not find correlation or significance. These results showed that the placement on renal dosing did not increase the likelihood that a patient would experience an increase in the total number of barriers experienced.

The analysis then analyzed each of the 45 questions to determine if there were any particular responses to questions that correlated with the change to a renal dosed regimen. The analysis used the same binomial scale on the 45 questions. Any question that more than half of a group (renal or normal) identified as a barrier went under further investigation. This yielded a total of 14 survey questions that fit this profile. These survey barriers are below in Table 2.

Table 2: Barriers to Adherence Survey Questions for Further Analysis

Question	Percent Who Responded	Barrier Identified
How hard or easy is it for you to manage the side effects of your HIV medications?	67%	Difficulty in managing the side effects to medications
How much bodily pain have you had during the past 4 weeks?	67%	Experiencing and dealing with bodily pain
During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)?	67%	Physical health problems limit ability to perform daily functions
During the past 4 weeks how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?	67%	Difficulty in performance of daily work due to physical health problems
It upsets me that the HIV medications I have been prescribed can cause side effects	66%	Fear of a medication's side effects
During the past 4 weeks, how much energy did you have?	63%	Lack of energy
I am worried that other people might realize that I am HIV+ if they see me taking my medications	58%	Fear that others may find out about HIV status if medications are taken in public
How hard or easy is it for you to take your HIV medications when you do NOT feel good physically	58%	Difficulty in taking medications when not feeling good physically
It upsets me that the HIV medications I have been prescribed can affect the way I look	57%	Negative feelings towards medications
How often do you use a pillbox to help keep track of your HIV medications?	57%	Not using a pillbox or other reminder device
It frustrates me to think that I will have to take these HIV medications every day for the rest of my life	57%	Frustration that HIV medications must be taken for life
I get frustrated taking my HIV medication because I have to plan my life around them	54%	Frustration in having to plan life around medications
How hard or easy is it for you to take your HIV medications when you do not feel good emotionally (for example, when you are depressed, sad, angry, or stressed out)?	53%	Not feeling good emotionally
How hard or easy is it for you to take your HIV medications when your usual routine changes (for example, when you travel or when you go out with your friends)?	50%	Changes in one's daily routine

For each of the questions above the analysis compared the baseline and final surveys for each participant. The analysis then summed the total number of patients that identified the question topic as a barrier for both the renal and normal dosing groups. Chi square tests using Yates correlation (since the size of the groups differed) compared the total number of barrier questions at baseline and exit time periods for both the renal dosing and normal dosing groups.

The expected outcome was that the analysis would identify certain barriers within the renal dosing group only, due to the additional challenges the patients in the renal dosing group faced. The data yielded from the analysis do not support this hypothesis. Of the 45 questions examined, only one (I am worried that other people might realize that I am HIV+ if they see me taking my HIV medications) was statistically significant. Surprisingly, this barrier was a problem for the normal dosing group and not the renal dosing group. Thus, the analysis found no barriers that significantly affected renal dosing patients more than normal dosing patients.

The lack of statistical significance in the data analysis most likely reflects the small sample size of the renal dosing group. While I found no statistical significance from the quantitative analysis, I decided to conduct a qualitative analysis by using an inductive grounded theory approach (Bernard 2004). I examined the 14 questions that patients identified as a possible barrier to adherence in order to identify possible trends in noncompliance. I reviewed each of the questions and identified themes that the questions had in common. An in-depth review of this analysis follows.

Discussion: Factors to Noncompliance and the Barriers to Adherence:

Through the use of the grounded theory analysis I found that there were some questions that the renal group identified as barriers, some that the normal group identified as barriers, and some questions that both groups identified as barriers.

The examination of these questions and their strategies led to several possible factors that may cause these barriers. These factors are below in Table 3.

Table 3: Factors to Noncompliance

Group Affected	Factor
Barriers that greatly affected patients in both groups	1) Emotional well-being and psychological mindset 2) Physical Factors that lie outside of a person's control
Barriers that affected patients on renal dosing more	1) Side Effects to medications 2) Physical Health problems
Barriers that affected patients on normal dosing more	1) Interruptions in daily life
Barrier that affected both groups but was not part of the survey. Field site personnel identified this barrier.	1) Health Literacy

Barriers for All Patients:

While not expected, the data revealed a series of barriers that affected patients in both of the groups. The quantitative analysis did not find this because the analysis focused on finding the differences between the two groups. The barriers that both groups identified are in Table 4.

Table 4: Barriers Identified by Both Groups

Question	Percent who Responded	Factor	Barrier Identified
It upsets me that the HIV medications I have been prescribed can cause side effects	66%	Emotional well-being and psychological mindset	Fear of a medication's side effects
How hard or easy is it for you to take your HIV medications when you do not feel good emotionally (for example, when you are depressed, sad, angry, or stressed out)?	53%	Emotional well-being and psychological mindset	Not feeling good emotionally
During the past 4 weeks, how much energy did you have?	63%	Physical factors that lie outside of a person's control	Lack of energy
How hard or easy is it for you to take your HIV medications when your usual routine changes (for example, when you travel or when you go out with your friends)?	50%	Physical factors that lie outside of a person's control	Changes in one's daily routine

The first two barriers identified by both groups related to the emotional wellbeing and psychological mindset of the patient. HIV+ patients suffer from a number of psychological and emotional issues. There are many aspects of living with HIV that cause distress for patients and if a patient is not feeling emotionally well, this can impact adherence (Tuck & McCain 2008). The fear of possible side effects from HIV medications can be very distressing to patients. As previously discussed, many medications can cause side effects, but HIV medications have some of the harshest side effects on patients. Thus, it makes sense to find these two barriers shared by both patient groups.

The second set of barriers identified by both groups focused on patients' experiences in dealing with physical factors that usually lie outside of their

control. A further review of the literature found that this trend is expected. It is well documented that many HIV+ people experience a lack of energy due to the virus, side effects from medications, or other health conditions (Adinolfi 2001).

The other physical barrier to adherence that both groups identified was difficulty in adhering to a medication regimen due to a change in daily routine. This particular barrier is also common among the HIV community although it is not exclusive to those on HAART. In fact most people, not just HIV positive people, forget or unable to take their medications when their routine changes (Rosner 2006 and Waller & Altshuler 1986). While these are well-known barriers, the data show that these barriers still exist for both populations and that further investigation into these barriers is necessary to understand the full impact that they have on adherence.

Barriers for Patients Placed on Renal Dosing:

While not statistically significant, the data revealed a number of barriers that affected patients in the renal dosing group more than those in the normal dosing group. These barriers are below in Table 5.

Table 5: Barriers for Patients Placed on Renal Dosing Schedules

Question	Percent who Responded	Factor	Barrier Identified
How hard or easy is it for you to manage the side effects of your HIV medications?	67%	Side Effects to medications	Difficulty in managing the side effects to medications
How much bodily pain have you had during the past 4 weeks?	67%	Physical health problems	Experiencing and dealing with bodily pain
During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)?	67%	Physical health problems	Physical health problems limit ability to perform daily functions
During the past 4 weeks how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?	67%	Physical health problems	Difficulty in performance of daily work due to physical health problems
How hard or easy is it for you to take your HIV medications when you do NOT feel good physically	58%	Physical health problems	Difficulty in taking medications when not feeling good physically

The first barrier identified by the renal group dealt with difficulties in the management of side effects. Both groups identified that knowing that HAART could cause side effects was barrier, but this finding may show an important difference between the two groups. It is unclear as to whether the normal group did not experience side effects or just did not have issues managing their side effects. It is clear that the renal group had issues in dealing with the side effects of their medications.

There may be several reasons why side effects are more burdensome for renal dosed patients. As previously discussed, studies revealed that medications like Tenofovir had the side effect of renal failure, which forced patients to receive dialysis treatments. The reception of dialysis treatments could very well explain this difference between the two groups.

The comorbidity of HIV and kidney problems may also explain this difference. Poor renal function increases the likelihood of adverse drug reactions and side effects (Jick 1977). The combination of these two factors results in a syndemic that may explain why this barrier is not shared with normally dosed HIV+ patients.

The remaining barriers all dealt with the physical health of the patient. While HIV may take its toll on the body and be quite painful, the additional issues in experiencing renal failure and undergoing constant dialysis treatments can be much worse. Kidney failure is extremely uncomfortable and causes intense pain in the kidney area (Pham et al. 2010). In addition to experiencing pain, dialysis treatments can leave a patient weak and unable to perform many of his/her everyday activities (Polaschek 2003). These barriers can affect whether a patient is actually able to take his/her medications and the medications can also affect the emotional mindset of the patient and how he/she feels about the medications and about HIV.

Barriers for Patients Placed on Normal Dosing:

Since the hypothesis was that renal dosed patients would have a harder time adhering to their medications, the data analysis attempted to find barriers unique to those patients who were on renal dosing. Although not expected, the data identified barriers that affected the normal dosed patients more than the renal dosed patients. These barriers are below in Table 6.

Table 6: Barriers for Patients Placed on Normal Dosing Schedules

Question	Percent who Responded	Factor	Barrier Identified
I am worried that other people might realize that I am HIV+ if they see me taking my medications	58%	Privacy	Fear that others may find out about HIV status if medications are taken in public
It upsets me that the HIV medications I have been prescribed can affect the way I look	57%	Privacy	Negative feelings towards medications
How often do you use a pillbox to help keep track of your HIV medications?	57%	Privacy/ Interruptions in daily life	Not using a pillbox or other reminder device
It frustrates me to think that I will have to take these HIV medications every day for the rest of my life	57%	Interruptions in daily life	Frustration that HIV medications must be taken for life
I get frustrated taking my HIV medication because I have to plan my life around them	54%	Interruptions in daily life	Frustration in having to plan life around medications

The first three of the barriers identified by the normal dosing group, revolved around issues dealing with privacy. The first of these barriers centered on the problem of taking one's medications in private. This was in fact the only barrier that was significant when compared between the two groups. Due to the small sample size, this finding cannot be representative of the greater HIV population. It is interesting though that for this group of patients, the fear of taking HAART in public is not a barrier for the renal dosed patients. A possible explanation may be that because these patients are so ill that their kidney problems make it too difficult to hide their health problems. If future studies show similar findings, then future researchers may want to examine this hypothesis.

Another explanation is the fact that the renal dosed group takes their medications less frequently making the taking of medications in private easier. It is also likely that the patients pair this barrier with the fear of disclosing one's HIV status. If

patients' immune systems are healthy, it can be easier to hide their status. Trying to hide an illness such as renal failure can be very difficult because of the pain that renal failure causes or the time necessary to receive dialysis treatments, which can leave patients weakened and unable to function normally (Johansen et al. 2003). It is possible that these factors may lead the renal patients to rely on others for help and in turn, disclose their HIV status.

The second barrier identified by this group also centered around the factor of privacy but dealt with the fear that the side effects of a medication could affect one's physical appearance. If an HIV medication causes physical side effects such as lipodystrophy (subcutaneous fat deposits found in the body) or lipoatrophy (the loss of subcutaneous fat), it is very hard for a patient to hide a side effect such as this or try to explain its causes. Similar to the second barrier, the third barrier focused on the use of a pillbox in remembering to take one's medications. Like a physical side effect, if a person uses a pillbox it may become difficult to keep this hidden and take the medications in private. Another explanation for this third barrier is that it may be difficult to use a pillbox due to the complexities of daily life.

The lack of the presence of renal impairment for these HIV+ individuals could explain this trend. HIV is unfortunately a highly stigmatized disease while renal impairment on the other hand is not (Rintamaki et al. 2006). The renal dosed individuals can disclose their renal impairment and used it as an explanation for their health problems. They could use this to explain why they take medications during the day and why they suffer from side effects to medications. Blaming some of these health problems on the renal impairment can allow these individuals to receive an understanding from others while still not disclosing their HIV status. The patients in the normal dosed group may not have another health condition to fall back on to blame their health problems to the public.

The final two barriers dealt with interruptions in daily life and showed that HIV+ patients can become frustrated with the ways that their medications affect them and their daily lives. As the effectiveness of HAART increased over time, HIV became a chronic disease and not just a death sentence. At the same time, there is no cure for HIV and reliance on HAART for the rest of patients' lives can be very frustrating. One reason why the renal dosed group did not identify these barriers might be because those on renal dosing face a more invasive treatment with dialysis. These patients may also view their kidney disease as a terminal illness. Many dialysis patients suffer from depression and are more likely to think about and commit suicide (Kurella 2005).

Because only the normal dosing group identified these barriers, these barriers should go under further investigation to understand their true nature. It may also be beneficial to understand why these are not barriers for the renal dosed patients in order to help future patients who are not on renal dosing.

Health Literacy:

While conducting the study, several of the site researchers reported that by taking part in the experiment, many of the patients became confident about their HIV medications. The site researchers reported that in the early stages of the study many of the patients did not know the names of their prescribed medications and could rarely describe what they looked like. The experimenters also noted that many of these patients did not know the difference between their HIV medications and medications used to treat other health conditions.

This trend occurred in both the renal and normal dosing groups, and at all five of the research sites. Added confusion existed for many of the renal dosed patients because the computer program did not measure adherence for their renal dosed medications. The site researchers had to leave these particular medications out of the system's memory when consulting the medical records. One on-site researcher reported that one patient insisted that he continued to take the renal

dosed medication every day. Yet the medical record and clinician's report showed that this was not the case.

As the study progressed fewer instances of medication discrepancies, amongst all patients, occurred. While this result was not surprising, because the patients grew familiar with the program over time, the field staff noted additional changes. Over time the patients felt confident about which medications the clinicians prescribed them. The site staff also stated that the patients appeared to display pride in knowing information about their medications. This was conveyed by the patients verbally telling the researchers how they felt or by the patients' facial and body expressions when they completed the pill-picker section.

The concept of health literacy can best explain this finding. Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (U.S. Department of Health and Human Services 2000). Health literacy is important for ARV therapy adherence because the more health literate HIV+ patients become the more likely they are to adhere to their HIV medication regimen (Kalichman, Ramachandran, & Catz 1999).

Simply by learning the names of their medications the patients became more informed about their health and their medications. Yet, knowing the name of a medication is far from being considered health literate; and health literacy among the HIV population is very limited. This is because, for the most part, the HIV population comprises individuals that are unfortunately marginalized by society. This includes populations such as minorities, gay men, prisoners, and IDUs. Many HIV+ people in America are from low socio-economic levels in society and lack the education and resources needed to learn about their disease.

The research team's interactions with HIV+ patients supported many of these stereotypes. The clinical sites locations were urban centers throughout the state

and nearly all of the patients suffered from a low socio-economic status. These patients demonstrated a low level of health literacy and appeared to know very little about their medications at the beginning of the study.

When a provider places a patient on renal dosing, the lack of health literacy becomes even worse. Most HIV medication regimens contain multiple medications. Yet, very few medications cause nephrotoxicity. So when a provider places a patient on a renal dosed regimen the nephrotoxic medication is usually the only one not taken every day. The provider, who once convinced the patient that he/she needed to take all his/her HIV medications every day, must now try to explain the changes to the patient's regimen. In a patient with low health literacy it can be very difficult for the provider to explain the changes in the medication regimen. It is even harder for the provider to try to explain why the change occurred and how, although the medication damaged the kidneys, adherence to the medication is necessary for viral suppression.

If a provider cannot convey this information in a way that the patient understands, adherence is at jeopardy because this is one of the main factors to adherence in the IMB model. It is also difficult for a provider to assess how much of the information the patient understands. Due to the power relations of the patient-provider relationship and cultural differences "the absence of discourses about rationing and the limits of therapeutic medicine reproduce old racialized tropes and lead us into explanatory circles when it comes to trying to understand racial health disparities" (Rousse 2010). If trust is not the foundation of the patient-provider relationship, meaningful and forthright conversations about adherence and barriers to adherence are unlikely to occur (Bangsberg et al. 2001 and Roberts 2000).

Renal dosing is relatively new to the HIV world. Further research on the health literacy of renal dosed patients can yield important information to providers and researchers. By increasing patients' health literacy providers can convey more-

accurate information to patients. With this information, patients can better understand their HIV, medications, and the therapeutic strategies on. This will be of extreme importance with the expected rise in numbers of renal dosed HIV patients.

Conclusion:

Adherence to an ARV medication regimen is fundamental for viral suppression. Identifying and addressing patients' barriers to adherence can increase rates of adherence. Renal dosing of HIV medications is still relatively new, and the literature on adherence to HAART for this group is severely lacking. Further investigation into understanding the management of side effects and how HIV and renal failure act on the physical health of patients is the first step to truly addressing the barriers these patients may face.

This thesis examined the barriers to adherence that HIV+ patients in the LifeWindows study identified. During the study some of the patients had their medications changed to a renal dosing regimen. The LifeWindows adherence survey positively identified several barriers to adherence. Statistical data analysis did not find a significant difference between the two groups as a whole or in relation to a particular question on the survey. Further exploration, from a qualitative perspective with the use of grounded theory, found possible trends among the groups. This thesis discussed possible explanations for the presence of these barriers in order to better understand these barriers. The presence of such barriers shows that more work is necessary in order to provide information and resources to these HIV+ patients.

Limitations:

The biggest limitation of this thesis was the small sample size of the renal dosing population. Due to the small sample size the power was insufficient. This may be why the data analysis did not find significance in the results. Unfortunately

this was unavoidable since the number of patients in the clinics placed on renal dosing was very small. In fact the providers placed about 2% of the sample on renal dosing. This sample may be a fair representation of the HIV population in America because only 2% of the population is on renal dosing (Hamzah & Post 2009). Yet, it is important to note that participation in the intervention arm did not affect the barriers identified or the rates of adherence for this group.

Another limitation of this study was that the computer program could not capture data on adherence for the renal dosed medications themselves. In order to garner a clearer picture of these barriers, data on adherence may be necessary. Another limitation was the dichotomizing of patient responses. To compare the patients' responses across questions the analysis required a standardized set of responses. Since the survey questions possessed a wide range of responses, the analysis required the responses to be binomial to be uniform. While this allowed comparison between questions it also limited understanding of the degree to which these barriers affected the patients.

The final limitation in this thesis was that the survey was a structured interview in which patients had a limited number of responses to choose from. This limitation did not affect the overall LifeWindows study, but it did affect the data captured on those patients whose providers switched them to a renal dosing regimen. Since there is very little known about renal dosing, obtaining an emic perspective would allow the renal dosed patients to explain more about their experiences with their medications.

Future Recommendations:

The analysis found 14 barriers to adherence that more than half of the population of either the renal dosed group or normal dosed group identified. Future research should test these barriers against a larger population of renal dosed patients. A larger population can accurately gauge whether or not these barriers

are significant. Also, a larger population may provide results that researchers could generalize to the larger HIV population.

While a larger population size of renal dosed patients is necessary, both groups identified four barriers. These barriers are of major concern because they impacted both groups. Therefore researchers should study these barriers right away. The barriers that only the normal dosed patients identified should also go under further investigation in relation to the renal dosed patients. It may prove useful to understand why certain barriers are not problematic for those patients on renal dosing.

It would be very instructive to conduct semi-structured interviews in future studies. These interviews could examine the questions on the survey in more depth and allow future researchers to obtain a more in-depth, emic perspective from the patients. The following examples provide reasons why an in-depth emic perspective is necessary to understand the illness narratives of the patients:

- 1) All patients identified the fear of side effects as a possible barrier to adherence. The normal group did not have a problem managing the side effects of their medications while the renal group did. This does not tell us if the normal dosed patients could manage their side effects effectively or if they did not experience side effects at all.
- 2) The renal group identified physical health problems as a barrier to adherence. While this barrier may exist for this population, the data do not tell us if this is related to the problems these patients have with their kidney failure or not.
- 3) Both groups identified difficulty in taking their medications when they did not feel emotionally well. According to the survey, not feeling emotionally well included: depression, sadness, anger, and stress. While these are all

negative emotions, there are differences between them. It may be necessary to determine which emotion patients experience and what caused the patients to feel that way. Treatment and coping for each of these emotions may be different. An argument could also be made that since most patients in the study did not feel emotionally well, all patients may need better mental health therapy.

As previously stated, the research conducted on adherence for HIV+ patients placed on renal dosing ARV medication regimens is scarce. This thesis is the starting point of adherence research for this population and can help guide future research. Researchers should use these results to further investigate this population to determine if these trends are unique to this study or are representative of the greater population. Since the rates of renal dosing of HIV medications will most likely increase in the coming years, it is important to understand the barriers to adherence for this population while its size remains small. By doing so, we can develop interventions and strategies to combat noncompliance before the population size increases. Thus, more research on this topic is necessary.

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Appendix

Table 7: LifeWindows Demographic Survey Questions

Item	Question	Response
1	What is your racial/ethnic background? (Please click all that apply.)	<input type="radio"/> African American or Black <input type="radio"/> Hispanic American or Latino(a) <input type="radio"/> White (not Hispanic) <input type="radio"/> Asian American <input type="radio"/> American Indian or Alaskan Native <input type="radio"/> Native Hawaiian or Other Pacific Islander <input type="radio"/> Other
2	Are you...? (Please click one.)	<input type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Transgender <input type="radio"/> Intersexed
3	What is the highest level of education you have completed? (Please click one.)	<input type="radio"/> Some high school or less <input type="radio"/> High school diploma or GED <input type="radio"/> Some college <input type="radio"/> College degree (BA, BS) <input type="radio"/> Some graduate school <input type="radio"/> Graduate degree (MA, JD, PhD, MD, etc)
4	What is your family income per year? (Please click one. If you don't know, please make your best guess.)	<input type="radio"/> Under \$5,000 <input type="radio"/> \$5,000 to \$10,000 <input type="radio"/> \$10,001 to \$20,000 <input type="radio"/> \$20,001 to \$30,000 <input type="radio"/> \$30,001 to \$50,000 <input type="radio"/> \$50,001 to \$75,000 <input type="radio"/> Over \$75,000
5	How many people are supported by this income, including yourself? (Please click one.)	<input type="radio"/> 1 (myself) <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4 <input type="radio"/> 5 <input type="radio"/> 6 <input type="radio"/> 7 <input type="radio"/> 8 <input type="radio"/> 9 <input type="radio"/> 10 or more
6	Where are you living right now? (Please click one.)	<input type="radio"/> Living on the street. <input type="radio"/> Living in an abandoned building. <input type="radio"/> Living in a homeless shelter. <input type="radio"/> Living in a halfway house, assisted living residence, or rehabilitation program. <input type="radio"/> Living in a friend's or family member's house or apartment. <input type="radio"/> Living in a house, condominium, apartment or room that you rent or own.
7	What is your sexual orientation? (Please click one.)	<input type="radio"/> Gay or lesbian <input type="radio"/> Straight or heterosexual <input type="radio"/> Bisexual <input type="radio"/> Unsure / don't know
8	How do you think you got HIV? (Please click all that apply. If you are unsure, please make your best guess.)	<input type="radio"/> Having sex with a man who had HIV <input type="radio"/> Having sex with a woman who had HIV <input type="radio"/> Sharing needles or works <input type="radio"/> Blood transfusion <input type="radio"/> Got it at birth <input type="radio"/> Don't know
9	In what year were you diagnosed with HIV? (Please click one.)	1980-2006
10	How many children do you care for in your home? (Please click one.)	<input type="radio"/> 0 (no children) <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4 <input type="radio"/> 5 <input type="radio"/> 6 or more children
11	What statement best describes your employment status? (Please click one.)	<input type="radio"/> Currently unemployed <input type="radio"/> Employed part-time <input type="radio"/> Employed full-time <input type="radio"/> On disability or sick leave <input type="radio"/> Retired

Table 8: LifeWindows Barriers to Adherence Survey Questions

Question	Response	Barrier Identified
Are you now taking a break from your HIV medications without having talked to your healthcare provider about it? (Please click one.)	<ul style="list-style-type: none"> <input type="radio"/> Yes <input type="radio"/> No 	Not adhering to ARV therapy
As long as I am feeling healthy, missing my HIV medications from time to time is OK.	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	Lack of knowledge about HIV and ARV therapy
During the past 4 weeks, how much did personal or emotional problems keep you from doing your usual work, school or other daily activities?	<ul style="list-style-type: none"> <input type="radio"/> Not at all <input type="radio"/> Very little <input type="radio"/> Somewhat <input type="radio"/> Quite a lot <input type="radio"/> Could not do daily activities 	Not feeling good emotionally
During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)?	<ul style="list-style-type: none"> <input type="radio"/> Not at all <input type="radio"/> Very little <input type="radio"/> Somewhat <input type="radio"/> Quite a lot <input type="radio"/> Could not do physical activities 	Physical health problems limit ability to perform daily functions
During the past 4 weeks, how much did your physical health or emotional problems limit your usual social activities with family or friends?	<ul style="list-style-type: none"> <input type="radio"/> Not at all <input type="radio"/> Quite a lot <input type="radio"/> Very little <input type="radio"/> Somewhat <input type="radio"/> Could not do social activities 	Difficulty in engaging in social activities due to health problems
During the past 4 weeks, how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?	<ul style="list-style-type: none"> <input type="radio"/> None at all <input type="radio"/> A little bit <input type="radio"/> Some <input type="radio"/> Quite a lot <input type="radio"/> Could not do daily work 	Difficulty in performance of daily work due to physical health problems
During the past 4 weeks, how much energy did you have?	<ul style="list-style-type: none"> <input type="radio"/> Very much <input type="radio"/> Quite a lot <input type="radio"/> Some <input type="radio"/> A little bit <input type="radio"/> None 	Lack of energy

<p>During the past 4 weeks, how much have you been bothered by emotional problems (such as feeling anxious, depressed, or irritable)?</p>	<ul style="list-style-type: none"> <input type="radio"/> Not at all <input type="radio"/> Slightly <input type="radio"/> Moderately <input type="radio"/> Quite a lot <input type="radio"/> Extremely 	<p>Not feeling good emotionally</p>
<p>How hard is it for you to pay for your HIV medications each month? (Please click one.)</p>	<ul style="list-style-type: none"> <input type="radio"/> Very hard <input type="radio"/> Hard <input type="radio"/> Neither hard nor easy <input type="radio"/> Easy <input type="radio"/> Very easy <input type="radio"/> I don't pay anything 	<p>Financial Issues</p>
<p>How hard or easy is it for you to get the support you need from others for taking your HIV medications (for example, from friends, family, doctor, or pharmacist)?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Lack of social support structures</p>
<p>How hard or easy is it for you to get your HIV medication refills on time?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Difficulty in refilling prescriptions</p>
<p>How hard or easy is it for you to make your HIV medications part of your daily life?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Difficulty in making medications a part of daily life</p>
<p>How hard or easy is it for you to manage the side effects of your HIV medications?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Difficulty in managing the side effects to medications</p>

<p>How hard or easy is it for you to remember to take your HIV medications?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Forgetting to take medications</p>
<p>How hard or easy is it for you to stay informed about HIV treatment?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Difficulty in gathering information</p>
<p>How hard or easy is it for you to take your HIV medications because the pills are hard to swallow, taste bad, or make you sick to your stomach?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Problem taking pills</p>
<p>How hard or easy is it for you to take your HIV medications when you are wrapped up in what you are doing?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Forgetting to take medications</p>
<p>How hard or easy is it for you to take your HIV medications when you do not feel good emotionally (for example, when you are depressed, sad, angry, or stressed out)?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Not feeling good emotionally</p>
<p>How hard or easy is it for you to take your HIV medications when you do NOT feel good physically?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Difficulty in taking medications when not feeling good physically</p>

<p>How hard or easy is it for you to take your HIV medications when you feel good physically and don't have any symptoms of your HIV disease?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Lack of knowledge about HIV and ARV therapy</p>
<p>How hard or easy is it for you to take your HIV medications when your usual routine changes (for example, when you travel or when you go out with your friends)?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Changes in one's daily routine</p>
<p>How hard or easy is it for you to talk to your healthcare provider about your HIV medications?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very Hard <input type="radio"/> Hard <input type="radio"/> Sometimes hard, sometimes easy <input type="radio"/> Easy <input type="radio"/> Very Easy 	<p>Poor patient-provider communication</p>
<p>How much bodily pain have you had during the past 4 weeks?</p>	<ul style="list-style-type: none"> <input type="radio"/> None <input type="radio"/> Very mild <input type="radio"/> Mild <input type="radio"/> Moderate <input type="radio"/> Severe <input type="radio"/> Very severe 	<p>Experiencing and dealing bodily pain</p>
<p>How often do you use a pillbox to help keep track of your HIV medications? (Please click one.)</p>	<ul style="list-style-type: none"> <input type="radio"/> Never <input type="radio"/> Once in a while <input type="radio"/> Half the time <input type="radio"/> Usually <input type="radio"/> Always 	<p>Not using a pillbox or other reminder device</p>
<p>I am worried that other people might realize that I am HIV+ if they see me taking my HIV medications.</p>	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	<p>Fear that others may find out about HIV status if medications are taken in public</p>

I am worried that the HIV medications I have been prescribed will hurt my health.	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	Fear of a medications' side effects
I believe that if I take my HIV medications as prescribed, I will live longer.	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	Lack of knowledge about HIV and ARV therapy
I don't like taking my HIV medications because they remind me that I am HIV+.	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	Negative emotions towards HIV and/or ARV therapy
I feel that my healthcare provider takes my needs into account when making recommendations about which HIV medications to take.	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	Poor patient-provider communication
I get frustrated taking my HIV medications because I have to plan my life around them.	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	Frustration in having to plan life around medications
I know how each of my current HIV medications is supposed to be taken (for example whether or not my current medications can be taken with food, herbal supplements, or other prescription medications).	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	Lack of knowledge about HIV and ARV therapy
I know how my HIV medications interact with alcohol and street drugs.	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	Substance abuse: drugs and/or alcohol
I know what the possible side effects of each of my HIV medications are.	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	Lack of knowledge about ARV therapy in relation to side effects

<p>I know what to do if I miss a dose of any of my HIV medications (for example, whether or not to take the pill(s) later).</p>	<ul style="list-style-type: none"> ○ I strongly disagree ○ I somewhat disagree ○ I neither agree nor disagree ○ I somewhat agree ○ I strongly agree 	<p>Lack of knowledge about ARV therapy in relation of missing a dose</p>
<p>I understand how each of my HIV medications works in my body to fight HIV.</p>	<ul style="list-style-type: none"> ○ I strongly disagree ○ I somewhat disagree ○ I neither agree nor disagree ○ I somewhat agree ○ I strongly agree 	<p>Lack of knowledge about HIV and ARV therapy</p>
<p>If I don't take my HIV medications as prescribed, these kinds of medications may not work for me in the future.</p>	<ul style="list-style-type: none"> ○ I strongly disagree ○ I somewhat disagree ○ I neither agree nor disagree ○ I somewhat agree ○ I strongly agree 	<p>Lack of knowledge about HIV and ARV therapy</p>
<p>It frustrates me to think that I will have to take these HIV medications every day for the rest of my life.</p>	<ul style="list-style-type: none"> ○ I strongly disagree ○ I somewhat disagree ○ I neither agree nor disagree ○ I somewhat agree ○ I strongly agree 	<p>Frustration that HIV medications must be taken every day for life</p>
<p>It upsets me that the HIV medications I have been prescribed can affect the way I look.</p>	<ul style="list-style-type: none"> ○ I strongly disagree ○ I somewhat disagree ○ I neither agree nor disagree ○ I somewhat agree ○ I strongly agree 	<p>Negative feelings towards medications because side effects can affect the physical appearance</p>
<p>It upsets me that the HIV medications I have been prescribed can cause side effects.</p>	<ul style="list-style-type: none"> ○ I strongly disagree ○ I somewhat disagree ○ I neither agree nor disagree ○ I somewhat agree ○ I strongly agree 	<p>Fear of a medication's side effects</p>
<p>Most people who are important to me who know I'm HIV positive support me in taking my HIV medications.</p>	<ul style="list-style-type: none"> ○ I strongly disagree ○ I somewhat disagree ○ I neither agree nor disagree ○ I somewhat agree ○ I strongly agree ○ No one that I care about knows I am positive 	<p>Lack of social support structures</p>

<p>My healthcare provider doesn't give me enough support when it comes to taking my medications as prescribed.</p>	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	<p>Lack of social support structures</p>
<p>Overall, how would you rate your health during the past 4 weeks?</p>	<ul style="list-style-type: none"> <input type="radio"/> Excellent <input type="radio"/> Very good <input type="radio"/> Good <input type="radio"/> Fair <input type="radio"/> Poor <input type="radio"/> Very poor 	<p>Being in a state of poor health</p>
<p>Skipping a few of my HIV medications from time to time would not really hurt my health.</p>	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree 	<p>Lack of knowledge about HIV and ARV therapy</p>
<p>There are times when it is hard for me to take my HIV medications when I drink alcohol or use street drugs.</p>	<ul style="list-style-type: none"> <input type="radio"/> I strongly disagree <input type="radio"/> I somewhat disagree <input type="radio"/> I neither agree nor disagree <input type="radio"/> I somewhat agree <input type="radio"/> I strongly agree <input type="radio"/> Not Applicable (I don't drink alcohol or use street drugs) 	<p>Substance abuse: drugs/and or alcohol</p>
<p>When was the last time you injected or "shot up" street drugs (such as heroin or cocaine)?</p>	<ul style="list-style-type: none"> <input type="radio"/> Never <input type="radio"/> Over a month ago <input type="radio"/> In the past month 	<p>Substance abuse: drugs and/or alcohol</p>

Table 9: LifeWindows Intervention Modules

Intervention Module	Description
Battle for Health	A video game in which patients battle infections, take ARV on-time to fight HIV, and use tools (e.g., pillboxes, alarms) to ensure that ARV are taken, even in challenging situations.
Bill the Pill	An animated character presents strategies for taking pills that are hard to swallow or taste bad, taking large numbers of pills, and taking medications that make one feel nauseous.
Celebrate Success	Offered to patients with perfect adherence. Patients create a personalized reward certificate and then learn about maintaining adherence over time.
Doc Talk	A video-based intervention in which patients can “ask” HIV doctors about a number of HIV-related issues, including HIV treatment, side effects, and resistance.
Felicia the Pharmacist	A video-based intervention in which patients are able to “ask” a pharmacist questions about their HIV prescriptions.
Focus on the Fight	Involves an activity that helps patients visualize the therapeutic effects of HIV medications.
Helping Hand	By playing the role of an adherence counselor to help other PLWHA overcome their barriers to adherence, patients learn strategies for dealing with their own adherence-related issues.
HIV, Drugs, and Alcohol	Discusses the effects of street drugs and alcohol on the body, street drug and alcohol interactions with ARV, and tips for staying healthy when using street drugs and/or alcohol.
Journey through the Bloodstream	An animated sequence that uses simple representations to explain T-Cells, CD-4 count, HIV, viral load, how ARVs help fight HIV in the body, and drug resistance.
Information Station	Describes services locally available for PLWHA, including counseling and support groups, mental health services, substance abuse treatment, and housing assistance.
Learning from a Missed Dose	Patients are taught to assess the circumstances surrounding a missed dose and learn to identify, understand, and overcome their barriers to adherence.

Lipodystrophy	Includes unscripted video accounts of four different personal experiences with lipodystrophy. The intervention also discusses possible causes and treatment options.
Match-Up	Patients create and print a personalized calendar on which ARV dose times are matched-up with recurring activities.
Med Minders	Describes tools and devices that can help patients take their medications on time, every time.
The Misadventures of Skip Sisdose	Uses humorous animation to provide tips for fitting ARV into one's daily life, taking ARV when one's routine changes, and taking ARV when others are around.
My Meds	A comprehensive resource that provides information about HIV medications, including dosing, side effects, drug interactions, and dietary restrictions for each medication.
Patient-Provider Communication	Addresses communication skills, with a focus on the doctor-patient relationship. Skills are presented through a series of video-based doctor-patient interactions.
Positive Voices	A video-based intervention in which participants can "ask" other PLWHA about their experiences with HIV and HIV medications.
Side Effects Solutions	Presents detailed information regarding side effects associated with HIV medications, and provides participants with tips and strategies for managing their side effects.
Stress Management	Patients learn about the nature of stress, particularly as it relates to living with HIV and ARV adherence. A variety of stress-reduction activities and strategies are provided.

Information courtesy of LifeWindows Project Team 2006: Draft of results.

Table 10: Listing of Strategies Addressed in LifeWindows

Learn more about your HIV medications, like how they're supposed to be taken or what to do if you miss a dose.
Learn how skipping your HIV medications from time to time can keep them from working for you and hurt your health.
Learn more about how your HIV medications work in your body.
Learn about the side effects of your HIV medications and ways to deal with them.
Learn about ways to hide your HIV meds and to take them in private.
Learn how to make your HIV medications part of your daily life and feel less frustrated about them.
Learn ways to feel better about your HIV and your HIV medications.
Work on ways to talk more effectively with your healthcare provider to get them to better understand your HIV medication needs.
Learn how taking your HIV medications as prescribed can help you to live longer.
Learn more about how HIV medications affect your health.
Learn how HIV medications can affect the way you look and what you can do about it.
Learn ways to get more support from others (such as friends, family, healthcare provider, pharmacist, etc.) for taking your HIV medications.
Learn how to get the information you want about HIV treatment.
Learn ways to get your medication refills on time.
Learn things you can do to help you remember to take your HIV medications, even when you're wrapped up in what you're doing or your routine changes.
Learn how to take pills that are too big, taste bad, or make you feel sick.
Learn about taking HIV medications when using alcohol or street drugs.
Learn how to deal with negative emotions and taking your HIV medications.
Learn why you need to take your HIV medications as prescribed, even when you're feeling healthy.
Learn ways to take your HIV medications when you're not feeling well.
Learn how to identify what gets in the way of you taking your medications.
Reward yourself for taking all of your HIV medications.

Table 11: Questions, Strategies, and Interventions used in LifeWindows

Question	Strategy	Intervention
Are you now taking a break from your HIV medications without having talked to your healthcare provider about it? (Please click one.)	Was not linked to a strategy	Not Applicable
As long as I am feeling healthy, missing my HIV medications from time to time is OK.	Learn how skipping your HIV medications from time to time can keep them from working for you and hurt your health.	Journey Through the Bloodstream, Doc Talk, Positive Voices
During the past 4 weeks, how much did personal or emotional problems keep you from doing your usual work, school or other daily activities?	Was not linked to a strategy	Not Applicable
During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)?	Was not linked to a strategy	Not Applicable
During the past 4 weeks, how much did your physical health or emotional problems limit your usual social activities with family or friends?	Was not linked to a strategy	Not Applicable
During the past 4 weeks, how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?	Was not linked to a strategy	Not Applicable
During the past 4 weeks, how much energy did you have?	Was not linked to a strategy	Not Applicable
During the past 4 weeks, how much have you been bothered by emotional problems (such as feeling anxious, depressed, or irritable)?	Was not linked to a strategy	Not Applicable
How hard is it for you to pay for your HIV medications each month? (Please click one.)	Was not linked to a strategy	Not Applicable

How hard or easy is it for you to get the support you need from others for taking your HIV medications (for example, from friends, family, doctor, or pharmacist)?	Learn ways to get more support from others (such as friends, family, healthcare provider, pharmacist, etc.) for taking your HIV medications.	Positive Voices, Doc Talk, Information Station, Patient-Provider Communication, Felicia the Pharmacist, Helping Hand
How hard or easy is it for you to get your HIV medication refills on time?	Learn ways to get your medication refills on time.	Felicia the Pharmacist, Helping Hand
How hard or easy is it for you to make your HIV medications part of your daily life?	Learn how to make your HIV medications part of your daily life and feel less frustrated about them.	Match-Up, Positive Voices, Doc Talk, Focus on the Fight, Stress Management, Med Minders, Misadventures of Skip Sisdose, Battle for Health
How hard or easy is it for you to manage the side effects of your HIV medications?	Learn about the side effects of your HIV medications and ways to deal with them.	Side Effects Solutions, My Meds, Felicia the Pharmacist, Doc Talk, Positive Voices, Lipodystrophy, Helping Hand
How hard or easy is it for you to remember to take your HIV medications?	Learn things you can do to help you remember to take your HIV medications, even when you're wrapped up in what you're doing or your routine changes.	Med Minders, Match-Up, Battle for Health, Positive Voices, Helping Hand, Misadventures of Skip Sisdose
How hard or easy is it for you to stay informed about HIV treatment?	Learn how to get the information you want about HIV treatment.	Patient-Provider Communication, Doc Talk, Felicia the Pharmacist, Information Station
How hard or easy is it for you to take your HIV medications because the pills are hard to swallow, taste bad, or make you sick to your stomach?	Learn how to take pills that are too big, taste bad, or make you feel sick.	Bill the Pill, Side Effect Solutions, Doc Talk, Felicia the Pharmacist, Battle for Health
How hard or easy is it for you to take your HIV medications when you are wrapped up in what you are doing?	Learn things you can do to help you remember to take your HIV medications, even when you're wrapped up in what you're doing or your routine changes.	Med Minders, Match-Up, Battle for Health, Positive Voices, Helping Hand, Misadventures of Skip Sisdose

How hard or easy is it for you to take your HIV medications when you do not feel good emotionally (for example, when you are depressed, sad, angry, or stressed out)?	Learn how to deal with negative emotions and taking your HIV medications.	Stress Management, Positive Voices, Information Station, Helping Hand
How hard or easy is it for you to take your HIV medications when you do NOT feel good physically?	Learn ways to take your HIV medications when you're not feeling well.	Side Effects Solutions, Bill the Pill, Doc Talk, Positive Voices, Helping Hand, Focus on the Fight
How hard or easy is it for you to take your HIV medications when you feel good physically and don't have any symptoms of your HIV disease?	Learn why you need to take your HIV medications as prescribed, even when you're feeling healthy.	Positive Voices, Doc Talk, Journey Through the Bloodstream
How hard or easy is it for you to take your HIV medications when your usual routine changes (for example, when you travel or when you go out with your friends)?	Learn things you can do to help you remember to take your HIV medications, even when you're wrapped up in what you're doing or your routine changes.	Med Minders, Match-Up, Battle for Health, Positive Voices, Helping Hand, Misadventures of Skip Sisdose
How hard or easy is it for you to talk to your healthcare provider about your HIV medications?	Work on ways to talk more effectively with your healthcare provider to get them to better understand your HIV medication needs.	Patient-Provider Communication, Doc Talk, Helping Hand
How much bodily pain have you had during the past 4 weeks?	Was not linked to a strategy	Not Applicable
How often do you use a pillbox to help keep track of your HIV medications? (Please click one.)	Was not linked to a strategy	Not Applicable
I am worried that other people might realize that I am HIV+ if they see me taking my HIV medications.	Learn about ways to hide your HIV meds and to take them in private.	Med Minders, Misadventures of Skip Sisdose, Felicia the Pharmacist, Doc Talk, Positive Voices, Battle for Health, Helping Hand
I am worried that the HIV medications I have been prescribed will hurt my health.	Learn more about how HIV medications affect your health.	Side Effects Solutions, Doc Talk, Positive Voices, My Meds, Lipodystrophy, Journey Through the Bloodstream, Helping Hand

I believe that if I take my HIV medications as prescribed, I will live longer.	Learn how taking your HIV medications as prescribed can help you to live longer.	Journey Through the Bloodstream, Doc Talk, Positive Voices, Battle for Health, Helping Hand
I don't like taking my HIV medications because they remind me that I am HIV+.	Learn ways to feel better about your HIV and your HIV medications.	Focus on the Fight, Positive Voices, Doc Talk, Stress Management, Information Station, Helping Hand
I feel that my healthcare provider takes my needs into account when making recommendations about which HIV medications to take.	Work on ways to talk more effectively with your healthcare provider to get them to better understand your HIV medication needs.	Patient-Provider Communication, Doc Talk, Helping Hand
I get frustrated taking my HIV medications because I have to plan my life around them.	Learn how to make your HIV medications part of your daily life and feel less frustrated about them.	Match-Up, Positive Voices, Doc Talk, Focus on the Fight, Stress Management, Med Minds, Misadventures of Skip Sisdose, Battle for Health
I know how each of my current HIV medications is supposed to be taken (for example whether or not my current medications can be taken with food, herbal supplements, or other prescription medications).	Learn more about your HIV medications, like how they're supposed to be taken or what to do if you miss a dose.	Felicia the Pharmacist, My Meds
I know how my HIV medications interact with alcohol and street drugs.	Learn about taking HIV medications when using alcohol or street drugs.	HIV, Drugs, and Alcohol, My Meds, Doc Talk, Positive Voices
I know what the possible side effects of each of my HIV medications are.	Learn about the side effects of your HIV medications and ways to deal with them.	Side Effects Solutions, My Meds, Felicia the Pharmacist, Doc Talk, Positive Voices, Lipodystrophy, Helping Hand
I know what to do if I miss a dose of any of my HIV medications (for example, whether or not to take the pill(s) later).	Learn more about your HIV medications, like how they're supposed to be taken or what to do if you miss a dose.	Felicia the Pharmacist, My Meds
I understand how each of my HIV medications works in my body to fight HIV.	Learn more about how your HIV medications work in your body.	Journey Through the Bloodstream, Doc Talk, Positive Voices

If I don't take my HIV medications as prescribed, these kinds of medications may not work for me in the future.	Learn how skipping your HIV medications from time to time can keep them from working for you and hurt your health.	Journey Through the Bloodstream, Doc Talk, Positive Voices
It frustrates me to think that I will have to take these HIV medications every day for the rest of my life.	Learn ways to feel better about your HIV and your HIV medications.	Focus on the Fight, Positive Voices, Doc Talk, Stress Management, Information Station, Helping Hand
It upsets me that the HIV medications I have been prescribed can affect the way I look.	Learn how HIV medications can affect the way you look and what you can do about it.	Lipodystrophy. Doc Talk, Side Effect Solutions
It upsets me that the HIV medications I have been prescribed can cause side effects.	Learn about the side effects of your HIV medications and ways to deal with them.	Side Effects Solutions, My Meds, Felicia the Pharmacist, Doc Talk, Positive Voices, Lipodystrophy, Helping Hand
Most people who are important to me who know I'm HIV positive support me in taking my HIV medications.	Learn ways to get more support from others (such as friends, family, healthcare provider, pharmacist, etc.) for taking your HIV medications.	Positive Voices. Doc Talk, Information Station, Patient-Provider Communication, Felicia the Pharmacist, Helping Hand
My healthcare provider doesn't give me enough support when it comes to taking my medications as prescribed.	Learn ways to get more support from others (such as friends, family, healthcare provider, pharmacist, etc.) for taking your HIV medications.	Positive Voices. Doc Talk, Information Station, Patient-Provider Communication, Felicia the Pharmacist, Helping Hand
Overall, how would you rate your health during the past 4 weeks?	Was not linked to a strategy	Not Applicable
Skipping a few of my HIV medications from time to time would not really hurt my health.	Learn how skipping your HIV medications from time to time can keep them from working for you and hurt your health.	Journey Through the Bloodstream, Doc Talk, Positive Voices
There are times when it is hard for me to take my HIV medications when I drink alcohol or use street drugs.	Learn about taking HIV medications when using alcohol or street drugs.	HIV, Drugs, and Alcohol, My Meds, Doc Talk, Positive Voices

When was the last time you injected or “shot up” street drugs (such as heroin or cocaine)?	Was not linked to a strategy	Not Applicable
During the Self-Report: if the Patient had Less than 100% adherence	Learn how to identify what gets in the way of you taking your medications.	Learning From a Missed Dose
During the Self-Report: If the Patient had 100% adherent	Reward yourself for taking all of your HIV medications.	Celebrate Success

Table 12: Barriers Addressed in LifeWindows

Being in a state of poor health
Changes in one's daily routine
Difficulty in engaging in social activities due to health problems
Difficulty in gathering information
difficulty in identifying barriers to adherence
Difficulty in making medications a part of daily life
Difficulty in managing the side effects to medications
Difficulty in performance of daily work due to physical health problems
Difficulty in refilling prescriptions
Difficulty in taking medications when not feeling good physically
Experiencing and dealing bodily pain
Experiencing bodily pain
Fear of a medications' side effects
Fear of side effects that affect physical appearance
Fear that others may find out about HIV status if medications are taken in public
Financial Issues
Forgetting to take medications
Frustration about having to take medications
Frustration in having to plan life around medications
Frustration that HIV medications must be taken every day for life
Issues dealing with privacy and disclosure of HIV status
Lack of energy
Lack of knowledge about ARV therapy in relation of missing a dose
Lack of knowledge about ARV therapy in relation to side effects
Lack of knowledge about HIV and ARV therapy
Lack of social support structures
Negative emotions towards HIV and/or ARV therapy
Negative feelings towards medications because side effects can affect the physical appearance
Not acknowledging one's accomplishments
Not adhering to ARV therapy
Not feeling good emotionally
Not feeling good emotionally
Not using a pillbox or other reminder device
Physical health problems limit ability to perform daily functions
Physical health problems limit ability to take medications
Poor patient-provider communication
Problem taking pills