

The medication experience of people living with HIV: From the understanding of the meanings of medication to the development of a conceptual framework of medication experience

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Dedication

Dedicated to people in need of chronic medications.

Abstract

This is a study investigating the medication experience of people living with HIV/AIDS and the influences on the patient's relationship with medications. The study was conducted from April 2011 to April 2012. The methodology of investigation was Grounded Theory. The methods included one-to-one in-depth interviews, journaling, and observations. The participants in the study were nine people living with HIV. The results suggest that there are two dimensions of experiences associated with HIV drug therapy. One is the life disruption and the other is the meaning that the patient ascribes to medications. The results of this study are presented as a theoretical visual model. The model intends to show the complexities of living with HIV and the factors influencing the patient's relationship with medications in HIV drug therapy. The author recommends the use of narratives in patient care as a standard practice to understand the patient's medication experience. In addition, the proposed model can be used as a pedagogical tool to teach students in the health care disciplines as it portrays the complexities involved in HIV medication taking in a relatively simple manner. The findings of this study contribute to the illness experience as well as medication experience literature. Lastly, the proposed model can be applied to other illness contexts in which the use of medications is a key strategy for improving the patient's quality of life.

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Chapter 1: Background information

Introduction

The human immunodeficiency virus (HIV) is a retrovirus that affects the immune system infecting its cells and debilitating their function. The HIV infection can take as long as 15 years to reach the stage of the acquired immunodeficiency syndrome (AIDS), the most advanced stage of HIV (World Health Organization, 2010). The World Health Organization estimates that 33.4 million people were living with HIV-AIDS in 2008 (World Health Organization, 2009), while 2.7 million are infected yearly. In the United States, according to the Center for Disease Control and Prevention (CDC), there are more than one million people living with HIV. Meanwhile, 21% of those infected are unaware of their infection (CDC 2010).

Whereas a diagnosis of AIDS used to mean certain death in short order, the emergence of antiretroviral therapy has situated HIV/AIDS as a chronic condition particularly with the discovery of protease inhibitors in 1996 (Wong & Ussher, 2008). While the viral infection cannot be completely eliminated with the available medications, reducing HIV-related morbidity as well as improving quality of life is highly achievable by the correct use of HIV drug regimens. The significance of medications in combating HIV is supported by extensive research. A randomized trial conducted over three years has shown the success of HIV medications in viral replication suppression in 80% of patients with "HIV RNA of less than 400 copies/mL [after] 48 weeks of treatment" (Gallant et al., 2004). Besides the selection of the best drug regimen, a high level of

adherence to the pharmacotherapy is required in order to achieve the goals of therapy. Studies have shown that 95% of adherence is the minimum necessary for virological suppression and a corresponding increase in immune response (Garcia, Schooley, & Badaro, 2003; Wong & Usher, 2008). Adherence is challenging, especially when people living with HIV/AIDS face complicated drug regimens, and particularly when there are severe side effects associated with antiretroviral medications.

Several studies have demonstrated that socio-behavioral factors influence low compliance to antiretroviral drug regimens (Gordillo et al., 1999; Wilson, Hutchinson, & Holzemer, 2002; Kalichman & Grebler, 2010). Despite research findings on social factors influencing health behavior, Wright states, "no combination of sociodemographic variables is reliably predictive of patients not following doctors' orders" (Wright, 2000). Although several studies have looked at adherence and compliance to medications, there is still a gap in studies looking at how people's medication experiences influence medication-taking behavior. This study aims to fill this gap by looking at how patients' medication experiences and the meanings they attach to them affect medication-taking behavior and how pharmaceutical care practitioners might help to address such issues.

This study applies qualitative methods to answer the research questions and to propose interventions to solve possible problems with medication-taking behavior. Using qualitative methodology to investigate patients' medication experiences and their influence on medication-taking behaviors proved to be an appropriate approach to research. The method of inquiry was mainly based on interviews with patients infected by HIV. The interviews allowed patients to share their views and understandings regarding

their experiences. “Life consists of retellings”, asserts Edward Bruner (1986). Since the goal of this study is the investigation of previous experiences that somehow impact current actions, the method drew support from biographical methods, as suggested by Becker. This author asserts that “biography tends to reorder significance of a life, reading that life backward and using past events as explanations for the current state of affairs (Becker, 1997).

The results of this study I believe will be useful for health care practitioners to better understand patients’ experiences and expectations regarding HIV treatment and support the development of clinical services that are able to effectively address their associated medication-related needs.

Rationale and need for the study

In 1999 I was assigned to a satellite pharmacy located in a large public hospital in the south of Brazil - 950 beds. As a third year pharmacy student with little experience in a hospital setting I was delighted to work on that location. The pharmacy was built as part of the Brazilian government efforts to increase access to antiretroviral therapy.

Outpatients living with HIV/AIDS comprised the clients of that pharmacy. In 1999, protease inhibitors had recently reached the market. That new class of drugs then changed the dynamics of antiretroviral therapy, positioning HIV/AIDS as a treatable chronic condition. Since 1996, Brazilian citizens have had the right to receive medications to treat HIV/AIDS and its complications. The government enacted a law granting this right.

At that time, the most common therapy for treatment naive patients – previously untreated patients – comprised AZT+3TC (zidovudine + lamivudine) combined in one pill, which should be taken two times a day. The third drug of the initial regimen was nelfinavir, for which the recommended regimen was 3 pills taken every 8 hours. Thus, a new treatment patient started his ritual with 11 pills a day, or 330 pills per month. This represented only the HIV drugs. The number of pills could be much higher for many patients as most of them needed some other medications to treat either the side effects of antiretroviral medications or opportunistic infections.

That satellite pharmacy did not have a full time pharmacist, which soon made me realize the shortcomings of how patients were treated with regard to their medication needs. Later on in my professional life I learned that this omission was not exclusive to that particular setting. In my view, relegating medications use as a matter of secondary importance on the part of both health care professionals and lay people is a widespread issue in different settings of the health care arena. In addition to my first lesson on the apathy of pharmacy services regarding patient care, I also learned that the presence of pharmacists in any given pharmacy did not necessarily mean that patients were receiving the best possible care, meaning the most effective and the safest drug therapy.

I spent over 5 years in the pharmacy. During that time I had the opportunity to meet several patients. The pharmacy had a database of over 1,000 patients, although not all had their prescriptions filled there. I learned a great deal from those patients. In truth, I should say that they were the most important motivators for my decision to go back to school to find the answers to the questions raised while working there. During the period

I spent at the pharmacy, I started to think about other aspects of medicine use that went beyond the pharmacological aspects. I was really intrigued by the idea of understanding how patients experience their treatments. I was curious to know how social determinants impact patients' behaviors regarding medication taking and their relationship with health care services. I wanted to know how someone who could barely read would be able to manage his or her medications and achieve positive clinical outcomes. I intuitively knew that the explanations for such questions could not be found in the level of patients' adherence, which was all the documentation system was able to tell us at that time.

The Brazilian HIV/AIDS Program and the World Health Organization's guidelines emphasize the importance of being adherent to medications as a means to decrease viral load and increase T helper cells. Studies support this assertion. Adherence though, seems too often to rely on the frequency in which someone visits the pharmacy. It rarely goes beyond the dispensing documentation system. This was the reality in Brazil at that time as it still is today.

In 2005, I left the hospital pharmacy in order to work at the city's Department of Pharmacy Services and one year later I was transferred to the Ministry of Health. In both the municipal and the federal level, I witnessed the fact that professionals who make decisions and design health/medication policies do not understand what it is like to live with HIV-AIDS or to be expected to take medications chronically.

It should be stated that in Brazil, comprehensive pharmaceutical care has been delivered in very few instances. At that time, the service was even less available. To my knowledge, there were no services offering the standard of care of pharmaceutical care

practice as proposed by Cipolle, Strand & Morley (1998; 2004), even at the federal level where I was working before I came to the United States.

As a pharmacy student as well as a licensed pharmacist, I was struck by the fact that patients are not being formally educated about medications and their use. In the HIV/AIDS pharmacy I saw many “experienced patients” with basic questions that should have been addressed before they started their treatments. In fact, medication use was not taken seriously by health professionals or by patients. By taken seriously, I mean lack of support on addressing patients’ questions and lack of follow-up on how patients use their medications. While most health care professionals are aware of the importance of medications, the patient still have no formal knowledge about their intricacies such as the reasons to take a medication, or what can be expected from them, or how one knows whether it is being effective and safe, or what are the best ways to take it to get the best possible clinical outcomes.

Thus, this research project emerged from my developed interest in the role medications can play in one’s life, the meanings medication might have for patients and how those understandings could impact their behaviors and, consequently, their health.

Specific Aims

The specific aims of this research are:

- 1) To describe and understand the meanings that people living with HIV/AIDS ascribe to their medications;

2) To understand how the use of antiretroviral medications might influence or disrupt patients' life experiences;

3) To understand how socio-psychological issues influence the medication experiences of people living with HIV/AIDS and, consequently, their medication taking behavior.

4) To understand the patient's needs, expectations, and concerns with regards to the use of antiretroviral medications;

5) To understand how the medication experience influences the development of drug therapy problems;

6) To propose a conceptual framework for the medication experience of people living with HIV/AIDS that will help practitioners provide a more patient-centered medication therapy management as well as more effective patient care, thus, improving the use of medications.

The medication experience framework will be the final product of this project. This framework will be presented as a visual model followed by its theoretical explanation. As a consequence of such knowledge, pharmaceutical care practitioners can tailor their practices to address a specific patient's drug-related needs and, consequently, improve the patient's medication experience.

Chapter 2: Literature review

This chapter presents the relevant literature in the areas of this study. The study aimed to understand the medication experience of people living with HIV/AIDS and its influence on medication taking behavior using pharmaceutical care practice, as proposed by Cipolle, Strand, and Morley (2004), as a theoretical framework. The review of literature mainly focused on the Human Immunodeficiency Virus and or Acquired Immunodeficiency Syndrome (respectively HIV and AIDS or HIV/AIDS when talked generically) and clinical as well as social aspects of drug therapy to treat people living with HIV/AIDS. Secondly, I address pharmaceutical care practice and its relevance to the context of HIV/AIDS as well as its intersection with the medication experience and illness experience.

Relevant to the present research is the description of HIV/AIDS and the key historical factors that have, in less than two decades, repositioned HIV/AIDS as a chronic controllable disease, different than a deadly disease in the beginning of the epidemic. The historical facts are relevant to the context of this research as the medications used in the treatment of HIV/AIDS have become the central piece in HIV/AIDS therapy. In the 30 years since the first reported case, HIV/AIDS drug therapy has evolved from no single effective drug in 1981 to more than 20 chemical agents in multiple combinations in 2011. Thus, this section starts with the literature on HIV/AIDS from 1981 until the current practices in 2011. The development of medicines to treat the condition is followed by the literature on pharmaceutical care practice and its rational decision-making process to

support the patient's drug therapy. The final part of this chapter describes the literature on medication experiences as well as meaning of medications with a focus on HIV/AIDS and its intersection with pharmaceutical care.

HIV/ADS: The beginning

On June 5, 1981, the Center for Disease Control (CDC) reported in its Morbidity and Mortality Weekly Report “five cases of *Pneumocystis carinii* pneumonia among previously healthy young men in Los Angeles (CDC, 1981).” In common, all five men were gay and either had previously or currently had cytomegalovirus. Nevertheless, they were not acquainted with each other, suggesting no direct physical contact within the individuals in the group. Two of those five men had already died. Most shocking was the fact that *Pneumocystis pneumonia* in the United States was restricted to “severely immunosuppressed patients” (CDC, 1981) and, according to government authorities, those men had no previous clinically identified immunodeficiency that could explain the rare pneumonia. For CDC officials, the causes of the mysterious outbreak could be linked to either an unknown aspect of homosexual lifestyle or a disease transmitted through sexual contact, causing the immune dysfunction and the consequent exposure to opportunistic infections such as pneumocystis or candidiasis (CDC, 1981).

Any association between cytomegalovirus as a direct cause of *Pneumocystis* was rejected early. A few weeks after the release of the CDC report, similar case reports started to pop up in several cities in the United States, including New York and San

Francisco (CDC, 2001). The case reports were followed by an increase in the requests of pentamidine — the therapy of choice for *Pneumocystis* — at the Center for Disease Control drug unit, which was the only distributor of such drug. The use of pentamidine was insufficient to heal those patients affected by the unknown disease.

The 1981 CDC Report is considered the first official publication on acquired immune deficiency syndrome — AIDS. Indeed, it was the official recognition of the most serious health epidemic of modern times. It represents a hallmark of a disease that 30 years later is claimed responsible for more than 25 million deaths (Smith and Whiteside, 2010) as well as more than 60 million people infected worldwide (Fauci, 2008). The CDC could not have imagined that in the modern era no other disease would have drawn so much attention as AIDS. By the end of 2009, there was more than 33 million people infected by HIV in the world (UNAIDS, 2010).

HIV/AIDS: Searching for causes

Despite the initial evidence on the possible cellular-immune dysfunction, the CDC was more inclined to concentrate the investigations of such immune suppression on some behavioral aspects that could be associated with gay male lifestyles such as promiscuity, use of amyl nitrate — also called poppers — and anal intercourse (Fee and Krieger, 1993). Nothing definitive was found.

From a biological standpoint, the focus on homosexual behavior soon turned out to be proved a mistake, particularly when cases of the rare pneumonia started to be

identified beyond the most prevalent group at that time, the so called ‘3Hs’ — homosexual males, heterosexuals who abuse IV drugs, and Haitians who recently entered the United States (Shilts, 2007). The fourth ‘H’ was added to the infamous acronym when cases of the mysterious immunodeficiency started to appear in non-gay hemophiliacs. Eventually, newborn children who had blood transfusion suddenly were identified with serious immune deficiency.

About a year after the first report on *Pneumocystis*, on July 16, 1982, the CDC issued a new Morbidity and Mortality Weekly Report accounting for three new cases of the same pneumonia. At that time, the disease was found in patients with “hemophilia A without other underlying disease” (CDCa, 1982). Contrary to the previous CDC Report, all three patients were heterosexual males. Moreover, despite the fact that the group shared the same immunologic as well as clinical symptoms as those previously identified with *Pneumocystis*, they did not share the ‘negative’ behavior as the other ‘3 Hs’ in the group. The hemophiliac cases reinforced CDC’s suspicions about a “possible transmission of an agent through blood products” (CDCa, 1982).

Later research confirmed CDC suspicions that an infectious agent was the underlying cause of the immunosuppression. The first groups infected by HIV have strongly affected the way that the disease was perceived by common sense in years to come. A telephone survey conducted by Herek et al. (2002) with adult United States Americans found that in 1999, almost two decades after the first official report on AIDS, one out of four people still believed that people who got AIDS through sex “have gotten what they deserve” (Herek et al., 1999). Even more disturbing is the fact that the same

study has found that approximately 25% of the people surveyed did not feel comfortable to have any sort of exposure with people living with HIV, either physical or symbolic contact (Herek et al., 1999). It suggests that the initial publicized strategies to investigate and understand the behavior of ‘risk groups’ rather than understanding the ‘risk behavior’ of those infected have had a strong contribution to the public perception about AIDS and its causes and consequences. Meanwhile, the stigma associated with the disease seems to have direct influence in the way people with HIV/AIDS perceive and deal with their drug therapy.

The term AIDS was coined in 1982 (Shilts, 2007) as the CDC received, between June 1, 1981, and September 15, 1982, reports of 593 cases of the disease in the United States and a 41% mortality rate (CDCb, 1982). The CDC defined AIDS as a “disease, at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease” or with a clinically diagnosed disease such as Kaposi Sarcoma or Pneumocystis carinii pneumonia as well as clinically unexplained opportunistic infections (CDCb, 1982). The severity of the disease was shown through high mortality rates among those affected. Moreover, the high mortality rates were boosted by the lack of an efficient pharmacologic agent to treat the disease and at the same time improving the immunologic system. The drugs available to treat the opportunistic infections were insufficient as the damage to the immune system was extremely severe as well as apparently irreversible.

The mystery surrounding the reasons for sudden and quick immunodeficiency of many patients came to an end about a year later. In 1983, in Paris, Luc Montagnier and

his research team published a paper suggesting evidence that AIDS was caused by a retrovirus (Barré-Sinoussi et al., 1983). A year later, another group of scientists, led by Robert Gallo, in the United States, published a paper with further evidence that the cause of AIDS was indeed a retrovirus (Popovic et al., 1984). If clinical evidences were insufficient to define a reliable strategy to fight an extremely serious public health issue, the identification of the agent causing AIDS was the piece needed to define further strategies to combat this serious threat. The retrovirus was later named the human immunodeficiency virus — HIV.

Uncovering the infection

HIV is a ribonucleic acid — RNA — virus that duplicates itself in the host cells, utilizing a series of enzymes with the aim of producing deoxyribonucleic acid — DNA — from the virus RNA genome in order to be incorporated in the infected people's genome. The resulting DNA is integrated into the host's genome using another enzyme, called integrase. The virus replicates itself as part of the host's DNA. As a result of the process, the virus is replicated naturally as part of the infected cell's DNA.

As soon as the HIV enters in the blood stream it starts its replication. Although many new HIV infected people do not present any symptoms, the most common sign of the HIV acute viremia appears in the first few weeks after being exposed to the HIV (2 to 6 weeks). The symptoms of such acute infection are similar to a common flu (fever, headache, tiredness). The HIV replication leads the human body to produce a HIV-

specific immune response. Moreover, this response somehow positions the infection in some degree of control. As a result, the concentration of HIV in the blood stream decreases.

The viral load resulting from the acute viremia is known as its “viral setpoint.” The viral setpoint displays the strength of the primary immune system. It varies among HIV infected people and those with higher viral setpoint have a quicker decline in CD4 cells count. In contrast, those with a lower setpoint can remain immunologically as well as clinically stable for longer periods. The most common markers to evaluate HIV infection are the number of CD4+ T cells — also known as T4 cells or T helper cells — and HIV viral load. The CD4+ cells are the first line of defense in the human immune system. The HIV affects these cells, decreasing their numbers and consequently facilitating opportunistic infections. The viral load for its part is the count per unit encountered in the blood. It is measured as HIV RNA per cubic millimeter of blood.

After being infected by HIV, an individual who does not receive any treatment for it can experience no symptoms for years to come. The time span between the first exposure to HIV and the first symptoms varies, but in general it takes around 10 years until the first signs of HIV infection. The clinical latency strongly suggests that the first identified people with AIDS in 1981 had been exposed to the HIV years earlier.

Despite the lack of symptoms, the virus continues to multiply rapidly through the body. It is estimated that the replication can reach as much as 10 billion viral particles each new day. The damage to the CD4 cells is progressive and continuous. Particularly important is that despite the lack of symptoms, an infected individual can transmit the

virus to another person through body fluids such as blood, semen, vaginal secretions, and breast milk (ADAM Encyclopedia PubMed). The virus is also present in other fluids like tears and saliva. Nevertheless, in the literature there are no records of transmissions through these fluids.

The clinical latency of HIV infection progressively damages the immune system destroying the CD4 cells. There is a clear distinction between HIV and AIDS. Although in this work the term HIV/AIDS is used to refer to someone infected by HIV, it is important to clarify this distinction. The HIV is the virus that causes AIDS. Therefore, someone who has AIDS is infected by HIV. While few people develop AIDS shortly after being infected by HIV, over a long term — it can be more than 10 years for some individuals — most HIV infected will develop AIDS — also known as full-blown AIDS. AIDS is the last stage of HIV infection and is characterized by a series of opportunistic infections. The CDC (CDC, 1992) defines AIDS as all HIV infected people older or equal to 13 year old who have either the following:

- a) less than 200 CD4+ T-lymphocytes/uL;
- b) a CD4+ T-lymphocyte percentage of total lymphocytes of less than 14%; or
- c) any of the following three clinical conditions: pulmonary tuberculosis,

recurrent pneumonia, or invasive cervical cancer. The expanded definition retains the 23 clinical conditions in the AIDS surveillance case definition published in 1987.

Racing for solutions

With the discovery as well as isolation of the agent causing AIDS, a scientific race took place at an unprecedented rate. The new knowledge about the virus and its mechanisms of replication allowed scientists to direct their research into finding either a cure or relief for those infected. To this date, a cure is still an unaccomplished goal while controlling the disease evolution in most individuals is a celebrated fact. Meanwhile, public health authorities began to screen blood supply in hospitals at the same time that preventive methods were publicized as a way to prevent new infections.

Despite public health authorities' efforts, preventing new cases of HIV and its massive spread was not a successfully achieved task. According to the World Health Organization estimation, in 2010 there were approximately 33 million people living with HIV/AIDS worldwide. Since the beginning of the pandemic, more than 25 million people have died from HIV infection (Smith and Whiteside, 2010). Data from the Joint United Nations Programme on HIV/AIDS — UNAIDS — shows that in 2009 there were 1.5 million people infected by HIV (1.2 – 2 million) in North America (UNAIDS 2010). In the United States, roughly 1.2 million are estimated to be infected, while 20% are unaware of their infection. It represents an adult prevalence of 0.5% of the adult population (15 to 49 years old). Despite its general decline, estimations are that each year 69,000 people are newly infected with HIV in the United States (UNAIDS, 2010).

HIV/AIDS: The chemical hope

The use of medications is the therapeutic tool most often used to treat many chronic conditions. The lack of an efficient drug therapy in the beginning of the HIV/AIDS epidemic was one of the most striking forces playing against the control of the disease. In the absence of pharmaceuticals to treat the infected people, authorities have unsuccessfully focused on preventive methods to prevent new HIV cases. No single chemical agent was approved to specifically treat HIV for at least the first five years of the epidemic. This changed in 1987 in what can be seen as a turning point in the history of AIDS epidemic.

The new player in the block

Symbolically, it was like the first signs of Spring after a long Winter in the northern hemisphere when, on March 21 of 1987, the Los Angeles Times published in its cover page the most exciting news on AIDS fight in the first decade of its existence. The first drug to treat people with AIDS in the United States was approved (Cimons 1987). The experimental drug zidovudine — AZT — was a breakthrough in the course of AIDS, though the American authorities emphasized that the new drug was not yet the so wanted cure to the deadly disease. Despite that, the new drug offered some hope to hundreds of people infected by the HIV. If, on the one hand AZT was not a cure, on the other, the freshly new drug could at least change the death face of AIDS. The approval of AZT was remarkable for hundreds of HIV infected individuals as well as to the health care community. By December 1987, the CDC AIDS Surveillance report showed an

astounding 20,303 adults and adolescents infected by HIV of a total of 49,006 cumulative cases in six years since the first report on AIDS (CDC, 1987).

With the advent of AZT, the so-called mono-therapy became the standard treatment to HIV/AIDS for years to come. The drug was the first antiretroviral of a class of drugs called nucleoside analog reverse transcriptase inhibitors — NRTI. The drug prevents virus replication by inhibiting the viral enzyme called reverse transcriptase. The reverse transcriptase is crucial to viral replication and is active in the beginning of the virus replication process.

In the modern era, the discovery of antiretroviral drugs may be placed as one of the greatest achievements in the pharmaceutical industry, changing completely the course of the infection. If in the beginning of the epidemic, people affected by HIV had no hope to survive longer than a year, after anti retroviral discovery, it changed drastically.

The hope of medicines

In the subsequent years following the approval of AZT, other drugs to combat AIDS were approved for human use. The second half of the 1990s was prolific in terms of antiretroviral approval. In 1995, there were already 5 different antiretroviral and one class available to combat AIDS, while in 2000, this number had tripled to 16 antiretroviral drugs in 3 different classes, more than 500 three-drug regimens, and more than 1,800 four-drug regimens available (Henry, 2000).

Though the existence of five drugs specifically designed to fight HIV may suggest a vast array of alternative therapeutic options, all the available drugs were of the same class of antiretroviral – nucleoside reverse transcriptase inhibitors. Due to having the same mechanism of action, rather than acting in synergy with each other, they were more an alternative for those individuals who experienced intolerance to AZT.

While the introduction of AZT can be seen as a turning point in AIDS history, it was with the approval of the protease inhibitors, almost a decade later, that a paradigm shift on HIV treatment took place in history. Indeed, the turn was from a death sentence within a year of infection in 1981 to a manageable chronic condition in the first years of the twenty-first century.

The protease inhibitors became the largest class in the anti retroviral arsenal (Wynn et al., 2004). The drugs in this class target a very late stage in the HIV replication, inhibiting the HIV protease enzyme from cleaving cells required for HIV replication (Wynn et al., 2004). With the new protease inhibitors and eventually the third antiretroviral class known as non-nucleoside reverse transcriptase inhibitor, triple-therapy became the standard treatment for all drug naive patients.

The non-nucleoside reverse transcriptase inhibitor is a selective inhibitor of the reverse transcriptase. As such, it acts synergistically with most of the antiretroviral drugs. The down side, though, is its drug-drug interaction requires a dose adjustment when used with protease inhibitors.

The availability of potent drugs to combat HIV has raised a new term in the lexicon of AIDS care. The combination of chemical agents in their different classes gave

birth to the concept of highly active antiretroviral therapy — HAART — or, both in layman language as well in the medical jargon, known simply as ‘the cocktail’ (Powderly, 2003).

Despite the fact that highly active antiretroviral therapy does not represent the cure of AIDS, it can be considered a breakthrough in the history of the disease. For AIDS researchers, it has revolutionized HIV treatment (Powderly, 2003). The downside, though, as in any revolution, is that it did not come without burden to those involved in such revolutionary movement. In the case of AIDS revolution, the burden was for those people living with HIV/AIDS who needed ‘the cocktail’. If, on the one hand, ‘the cocktail’ has given hope to people suffering from the disease, on the other, the challenges facing those in treatment were at high stakes. The hope came in the viral load count decrease as well as an increase in the immune system of HIV positives. Nevertheless, the burden was a demanding discipline to stick with the daily drug regimen and its long list of side effects, toxicity, and a complicated thread of drug interactions (Wynn et al., 2004).

Laboratory tests are key factors to support the initiation of a treatment. The World Health Organization recommends that all HIV infected with CD4 counts less or equal to 350 cell/mm³ should start taking medications (WHO, 2010) regardless of being asymptomatic or not. The WHO strongly recommends it despite “low quality of evidence” for such recommendation (WHO, 2010). The use of HIV drug therapy is thus initiated as soon as the person is known to be infected. In many cases, when acute viremia is identified, the treatment is initiated, even in the absence of any symptoms.

Although the lack of symptoms may suggest that the virus is not replicating, the reality is that the virus continues to multiply at high rates over the course of the infection in the absence of treatment. The progressive destruction of CD4 cells and its consequential damage to the immune system can be prevented — or diminished — with the initiation of drug therapy as soon as possible. Therefore, drug therapy plays a pivotal role in preventing early cases of AIDS. In fact, few people develop AIDS shortly after becoming infected. Although after a period of ten years, the majority of untreated HIV infected people develops AIDS.

More recently, the HIV medications were placed in an even more important place in the HIV/AIDS therapy. A large clinical trial, which recently published initial findings, has suggested that early initiation of HIV drug therapy may reduce the risks of transmitting HIV among HIV-serodiscordant partners (a couple in which one of the partners is HIV positive while the other is negative). Early initiation of HIV drug therapy is found to be a key factor in decreasing the risks of HIV transmission (HPTN Press Release, 2011).

AIDS under control

With the availability of anti retroviral drugs specifically designed to combat HIV, the AIDS epidemic suddenly became a controllable disease. In 1994 as well as 1995, before potent antiretroviral drugs, HIV infection was the leading cause of death among persons 14 to 44 years old. Particularly in 1995, the HIV disease was responsible for

causing death to about 32,000 people, representing 20% of all deaths in this age group. This number dropped to about 5,000 deaths in 2006 — about 4% — which represents the 6th leading cause of deaths among this age group (CDC, 2011). New infections in the United States are estimated to be approximately 70,000 cases per year. Death rates due to HIV infection have dropped considerably mainly due to the advance of antiretroviral drugs.

The decrease of death rates due to AIDS is indisputably from highly active antiretroviral therapy. Its discovery is acclaimed as one of the most notable achievements of medicine in the last century.

In HIV/AIDS, adherence to antiretroviral drugs is a key factor in HIV/AIDS drug therapy. Studies suggest that an adherence of 95% to the medications is necessary to keep viral load undetectable at the same time that the number of CD4 cells in the organism increases (Paterson et al., 2000).

Today, after 30 years of the first cases of AIDS, whereas HIV/AIDS has not yet a cure, anti retroviral medicines represent the most important intervention to control the HIV infection progression. While drug therapy is the most important tool to treat people with HIV, the challenges facing the success of such therapy are extremely high. Most of the literature on AIDS treatment focuses on the importance of high levels of adherence. Adherence is seen as a key factor for the success of the therapy. Furthermore, the lack of adherence to the prescribed treatment is seen as a deviation of what would be expected from a patient. The limitation of that argument is that the deviation as seen normatively by those who prescribed a complicated regimen is often different than from how those

who need the medications define what is important to them. It is often a one-sided view of an issue, and frequently not from those who experience the challenges of being adherent (Wright, 2000).

Common medical sense tends to view the problem of adherence as something attributed to a particular group of people. Nevertheless, research does not support this perception. Wright (2000) claims that there is no typical non-adherent type of patients observed empirically in clinical settings. Rather, the author claims that the lack of compliance is so common to patients in use of chronic medicines that this becomes the standard practice. Therefore, the deviation seems to be in fact exactly the opposite, a full adherent patient.

The challenges

The efficacy of antiretroviral drugs to control HIV infection is widely granted as a success. The triple drug therapy used to treat patients with HIV is the standard approach to HIV infected patients. As previously noted, the success is highly dependent on high levels of adherence to antiretroviral drugs. However, the high adherence proclaimed as the key factor to the success of drug therapy of AIDS comes at high stakes. Multiple factors are observed as impediments to the achievement of full adherence. One of the main constraints of HIV drug therapy is the large number of side effects common to most antiretroviral drugs. It includes a large set of clinical dysfunctions including gastrointestinal disruptions, hepatic toxicity, abnormality of lipids balance, disturbance of

metabolism, and sexual dysfunction (Wynn et al., 2004). These symptoms are frequently associated with anti retroviral pharmacotherapy discontinuation as many individuals cannot deal with such symptoms. For instance, a study conducted with patients in use of highly active anti retroviral treatment found that as much as 25% of patients discontinue anti retroviral therapy as a result of the complications of their regimen (Monforte et al., 2000).

In general, most of the gastrointestinal symptoms like nausea and vomiting are experienced by antiretroviral naive patients for as long as 6 months of treatment. Nevertheless, for some individuals, it may stay for as long as the treatment is administered (Wynn et al., 2004). Researchers as well as clinicians claim that in order to prevent drug discontinuation that may result in clinical failure or drug resistance, preventing and treating such symptoms is one of the most relevant strategies to help patients cope with the challenge of being adherent (Henry 2000; Wynn et al., 2004).

The large number of pills that patients need to swallow daily is another complication of HIV drug therapy, particularly after the introduction of protease inhibitors (Krieger, 1996). The standard treatment for antiretroviral naive patients after the release of protease inhibitors and the introduction of HAART was 11 pills per day divided by at least four times per day. The burden of swallowing large quantity of pills was partially addressed with the approval of the one-pill-per-day called Atripla® (Killingley & Pozniak, 2007). The pill is a combination of three drugs — efavirenz, emtricitabine, and tenofovir. It is the first of its kind (Deeks& Perry, 2010). It was widely celebrated as a potential drug to improve adherence. Nevertheless, although the highly

praised drug was an undeniable improvement in the demanding HIV treatment, like most anti retroviral drugs, Atripla® has a long list of side effects that may impact the highly expected adherence. For a treatment that requires a life commitment, side effects are still a strong factor affecting adherence. In a literature review of studies looking at the association between Atripla® and adherence in PudMed, no single study is published yet. The celebration of a one single pill per day is a legitimate celebration. Nonetheless, the still frequent incidence of side effects and the strong focus on adherence may suggest a drug-centered approach in HIV care. The simplistic view that a single drug is the answer for high levels of adherence may overlook the problem.

The single drug per day regimen has placed the HIV treatment in another level. It seems to be indisputable that the single regimen may be extremely positive to people living with HIV and it should be carefully analyzed when non-adherence is observed. Despite the association of large number of pills and low adherence being widely accepted, clinicians need to be careful when addressing patients who are non-adherent to their recommendations. The adherence-centered focus in HIV care may impact the way deviance from a completely full adherence becomes a taken-for-granted discourse that suggests a medical centered approach to patient care (Conrad, P. 1987). The non-adherent behavior is not necessarily perceived as an issue by many patients (Donovan and Blake, 1992). Rather, as Conrad points out, non-adherence can be seen as a concept derived from the physicians' necessity to solve their own problems as their medical duties are tailored to fix patients' problems (Conrad, 1987). Therefore, by focusing on adherence, clinicians may overlook deeper complexities of being on drug therapy, particularly with

complicated regimens and their associated toxicity. This suggests a shift in the current paradigm to allow patients to raise their voice and be more participative in their health care.

The need for patient centered care

The implications of AIDS treatment urge for a larger focus on the patient, which places the patient at the center of the care process and takes his or her considerations as legitimate claims. Essentially, a patient-centered standard practice in AIDS care is what may be the most effective way to care for this population. Proponents of such model of care eloquently claim that intentional non adherence — which occurs when an individual, in spite of understanding the treatment, consciously decides not to take it — can be reversed through individualized approaches that address the individual's decision for not coping with treatment (Roberts and Mann, 2003). Particularly relevant to AIDS drug therapy, individualized care may offer a settlement for the different perspectives that clinicians and patients may have. The biomedical emphasis, in which adherence seems to be the foundation, needs to incorporate the social aspects that influence patients' behaviors toward medication taking. For instance, what are perceived as severe side effects of antiretroviral drugs by health care providers are related to their systemic effects such as liver toxicity and metabolic disruption. Nevertheless, effects perceived by health care providers as less severe, like sexual dysfunction, diarrhea and vomiting, are the most frequent complaints preventing drug continuation by those in treatment (Lallemant et al.,

2002). A pertinent question to this reality is: what are the perceptions of patients regarding the side effects that may prevent them to be adherent to a prescribed treatment?

The adherence or compliance discourse on HIV/AIDS care needs to be expanded to formally and systematically incorporate the patient's perceptions, beliefs, and expectations toward their drug therapy.

Moreover the decision of whether to stick with the treatment or not is constantly renegotiated within individuals themselves (Roberts and Mann, 2003). The decision is a result of an internal choice that involves individuals' views of life such as spirituality, physical health perceptions, as well as social interactions with other individuals (Roberts and Mann, 2003). These researchers suggest reasons beyond the physical ones. For instance, it may encompass deep feelings and emotions as being in anti retroviral therapy symbolically referred to as an "emotional prison" (Roberts & Mann, 2000). The authors claim that perhaps, the most important strategy to help patients cope with their treatment is a "need for routine, ongoing health care professional-patient communication regarding antiretroviral adherence" (Roberts & Mann, 2003). It should be stressed, though, that simply reinforcing the need for adherence when patients start their treatment is not a sufficient action. Indeed, patient-provider relationship is an ongoing process, requiring continuing communication during the whole course of treatment as it was previously observed that the decision to take drugs is continually questioned and may change over the course of time (Roberts & Mann, 2003). Individualized care has increased relevance in HIV care when the severity of side effects is perceived differently by health care providers and patients. HAART seems to have these two sets of side effects. Patients

complain about side effects but wonder whether the effects are from the drugs they are taking or from the HIV infection itself (Meystre-Agustoni et al., 2000). The uncertainties perceived by the patients are pertinent to their reality, although some patients “think they are not” (Meystre-Agustoni et al., 2000).

It should be underscored that a more recent sociological analysis of adherence presents some criticisms to this patient-centered discourse or humanistic critique of compliance. For Mykhalovskiy (2002; 2004; 2008), the view of biomedicine as an oppressive negative power and of physicians as professionals who discount patients’ experiences is too limited and simplistic. He uses the Foucaultian understanding of power- multifaceted, everywhere and productive - to look at adherence. In this context, adherence is shaped by multiple forms of powers, including, for example, discourses of public health, AIDS services organizations and patients’ own resistances. An ethnographic study that explored how patients living with HIV/AIDS take HAART on a daily basis indicates the multiple and complex interplay of different ways of knowing, besides biomedicine, that shape adherence discourses (Mykhalovskiy & McCoy, 2002). Notions of compliance/adherence have also been incorporated by the pharmaceutical industry and by communities of patients, which often tend to define the ‘good, assertive, responsible and compliant HIV patient’. Therefore, it should be noted that the ideas around adherence involve multiple discourses with several sites of production, which makes it impossible to simplify its analysis.

Pharmaceutical care practice and medication therapy management

The Department of Health and Human Services Panel on Antiretroviral Guidelines for Adults and Adolescents is a working group that has the primary goal of providing recommendations for HIV care practitioners. Their recommendations are based on current knowledge on anti retroviral drugs available to be used to treat these populations in the United States. The Panel, as they are known, recommends the initiation of antiretroviral therapy to all patients with a history of an AIDS-defining illness or, in the absence of that, with a CD4 count less than 350 cells per cubic millimeter. In addition, treatment is also recommended for patients with CD4 counts between 350 and 500 cells per cubic millimeter. Nevertheless, this recommendation holds a moderate status from the group. For patients with CD4 above 500 cells per cubic millimeter, “panel members are evenly divided, [with] 50% favor starting [anti retroviral drugs] at this stage of HIV disease, [while] 50% view initiating therapy at this stage as optional” (Panel, 2011).

Henry (2003) sustains that “the major goal of HIV therapy is to maintain the long-term health of the patient while avoiding drug- related toxicity and preserving viable future treatment options” (Henry, 2003). He continues by stating that “current practice focuses on the early suppression of viremia, yet the outcome of that approach may not be in the best interest of individual patients or populations” (Henry, 2003). The thesis for such concern relies on the fact that premature initiation of anti retroviral drugs may expose the patient to the potential side effects as well as the toxicity of anti retroviral drugs. The long-term risk is even more risky as the resistance to anti retroviral drugs and

its limited options may threaten the success of the treatment. Thus, the best long-term strategy to maximize adherence and, therefore, increase clinical as well as immunological success on HIV care is to work individually with patients (Henry, 2003).

In an interesting perspective article published in the *Annals of Internal Medicine* in 2000 (Henry, 2000), a clinician discusses the urgent need to better understand and take into consideration the side effects associated with the long-term treatment of patients living with HIV/AIDS. He calls attention to the lipid abnormalities and the increased risk for cardiovascular disease as the population ages. Henry underscores that the common side effects associated to drug therapy - metabolic problems, hepatitis, pancreatitis, neuropathy, drug-related gastrointestinal symptoms, bone problems (59, 60) and nephrolithiasis - are replacing the AIDS-related events at his clinic. All these side effects dramatically impact patients' quality of life. He also emphasizes the need for the monitoring of the long-term effects of drug-therapy as well as the use of simpler medications and more individualized care. He states: "It is frustrating that an increasing number of clinical studies focus more on what is good for the drug than on what is good for the patient."

This clinician emphasizes that even though most of the current research is focused on the development of new expensive and toxic agents to treat anti-retroviral naive patients, most patients in practice have been previously treated. From his perspective, even though better drugs are needed, the highest priority should be to determine the optimal use of drugs that are already available.

In light of all the complexity of HIV treatment and its complications, any service that aims to have a patient-centered focus should “incorporate extended discussions with the patient about his or her priorities and wishes” (Henry, 2000). Also, it is common to encounter patients living with HIV-AIDS with serious untreated diabetes, hypertension and arteriosclerosis, which call for a more comprehensive care of these patients.

With the need for a comprehensive assessment of all of a patient’s drug therapy in mind, in recent years visionary scholars within the profession of pharmacy proposed a paradigm shift for the profession and, why not, for the whole health care system (Hepler & Strand, 1990; Cipolle, Strand, & Morley 1998; 2004). These scholars proposed a reinvention of the pharmacy profession as they defined pharmaceutical care practice as its new mission. The practice has evolved from clinical pharmacy to a patient-centered practice that can revolutionize the way health care professionals take care of patients focusing on their medication needs. Pharmaceutical care is a professional practice in which the pharmacist takes responsibility for meeting all the drug related needs of a patient- guaranteeing that all medications the patient is taking are indicated considering all of his or her co-morbidities, that the medications are the most effective and the safest possible and that the patient is able and willing to take the medications as recommended- and is held accountable to this commitment (Cipolle, Strand, & Morley, 2004). As any other professional practice in health care, pharmaceutical care has a philosophy of care, a patient care process and a practice management system that provides all the necessary resources for the pharmacist practitioner to care for patients and meet their medication needs. Interestingly, pharmaceutical care provides the practitioner with a rational,

standardized and consistent process to make decisions about drug therapy that are centered on the individual patient. It should be emphasized that this is a first in the health care system. Thus, with the advent of pharmaceutical care, the focus of the pharmacist started shifting from the product to the patient. As Cipolle once said, “drugs do not have doses, patients have doses” (Cipolle, 1996).

More than assessing patients’ needs with regards to medications, it is expected that the pharmaceutical care practitioner strive to understand how patients develop relationships with their medications and how they ascribe meanings to them (Shoemaker & Ramalho de Oliveira, 2008; Shoemaker et al., 2011; Ramalho de Oliveira et al., 2012). In addition, an alliance between the pharmacist and the patient should develop as a result of this practice. Pharmaceutical care has positioned the pharmacist in a more pro-active position in the health care team with the goal of improving the way medications are used by those who need them and ultimately improve patients’ quality of life (Ramalho de Oliveira, Brummel, & Miller, 2010). For instance, a pharmaceutical care practice with over 10 years of existence in which the pharmacist is an integral part of the health care team in primary care ambulatory clinics, shows that this clinical service improves patients’ clinical outcomes while decreasing the total health care costs. Moreover, it delivers high levels of patient satisfaction (Ramalho de Oliveira, Brummel, Miller, 2010).

Pharmaceutical care practice has been accepted as the new mission of the profession of pharmacy, even though it still is not the standard of pharmacy practice in most health care settings. Because pharmaceutical care is a professional practice focused on improving drug therapy outcomes, a pharmacist practicing it might have a key role as

a health care provider to people living with HIV/AIDS. In this regard, how can the pharmaceutical care practitioner better care for people infected with HIV? The question still remains to be answered. Although the question is not at the core of this research, this study can certainly contribute to the construction of pharmaceutical care practices to better meet the needs of this specific population. It is important to mention that pharmaceutical care practice was originally envisioned as a generalist practice and its use in specialty settings, as in the area of HIV-AIDS, requires further investigation. However, it should be emphasized that the pharmaceutical care practitioner is trained to provide the same standard of care regardless of the patient's medical condition or the medication the patient is taking. Moreover, the specialization is an expected step in the trajectory of consolidation of this new professional practice. In other words, even though pharmaceutical care was created as a generalist practice, as any other professional practice, as the practice gets implemented, delivered and matured, specialization becomes a natural demand of the practice. In the case of HIV-AIDS, the pharmaceutical care practitioner, or the medication therapy management (MTM) pharmacist, will use the same patient care process as used by the generalist practitioner even though he or she will have to apply a specialized type of knowledge to meet the more complex medication needs of people living with HIV/AIDS.

Medication Therapy Management (MTM) services were established by the Federal Government in the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (US Department of Human Health and Services, 2003; Ramalho de Oliveira et al., 2010). It encompasses elements of pharmaceutical care

practice focusing on the patient and aiming at "optimized therapeutic outcomes through improved medication use" (Ramalho de Oliveira et al., 2010). Thus, Medication Therapy Management is the clinical service that is formally recognized, reimbursable and measureable by the government and health plans when pharmacists provide pharmaceutical care. It is expected that pharmacists are the prospective MTM providers, although "other qualified providers" (Ramalho de Oliveira et al., 2010) are also allowed to provide such services. According to the Centers for Medicare and Medicaid Services (CMS) "existing standards and performance measures are insufficient to support further specification for MTM services and service level requirements, and therefore plans need the discretion to decide on which methods and which providers are best for providing MTM services" (Ramalho de Oliveira et al., 2010). Nevertheless, for this research, MTM is defined utilizing the standards of pharmaceutical care practice as proposed by Cipolle, Strand and Morley (Cipolle, Strand, & Morley, 2004). In this context, MTM is a "standard of care that ensures each patient's medications are individually assessed to determine that each medication is appropriate for the patient, effective for the medical condition, safe given the comorbidities and other medications being taken, and able to be taken by the patient as intended" (Patient-centered Primary Care Collaborative, 2010). Moreover, it "includes an individualized care plan that achieves the intended goals of therapy with appropriate follow-up to determine actual patient outcomes. This all occurs because the patient understands, agrees with, and actively participates in the treatment regimen, thus optimizing each patient's medication experience and clinical outcomes" (Patient-centered Primary Care Collaborative, 2010).

In the context of HIV/AIDS, the application of the philosophical framework and the patient care process as proposed by pharmaceutical care practice is still in its initial stages. There are few studies evaluating pharmaceutical care interventions in people living with HIV/AIDS (Colombo 1997; Geletko & Poulakos 2002; Foisy & Akai 2004; de Maat 2004). Most focus on adherence to antiretroviral drugs since it seems to be the main focus of pharmacotherapy on HIV/AIDS care as a way to improve clinical outcomes. These studies suggest that interventions provided by pharmacists can significantly improve overall health indicators of patients with HIV/AIDS (Foisy & Akai 2004; March, Mak and Louie, 2007). Long term increase in CD4+ counts is shown as a primary result of pharmacists' interventions along with a decrease in viral loads as well as drug-related toxicities (March, Mak and Louie, 2007).

It should be noted that as the pharmaceutical care practitioner uses the rational decision making process to assess all of a patient's medications, including prescribed, over-the-counter and nutritional supplements, it could be inferred that she or he tacitly assumes that the best possible therapeutic intervention is the use of medication, since she or he always looks at the patient's symptoms, or health problem, as being possibly caused by a medication or as being fixable by a medication. But, what makes this approach patient-centered is the fact that the provider actually focuses on the patient, his experiences and perspectives as it is lived on a daily basis considering his social context. The pharmaceutical care practitioner strives to build a therapeutic relationship with the patient in which the individual's expectations, wishes and concerns are taken into consideration in the moment of developing a care plan. Actually, the care plan is expected to be a co-

creation between pharmacist and patient. In this context, the entire care process involves clear communication, negotiation and shared-decision making.

As emphasized by Conrad (1987), a more patient-oriented care is a necessary condition to achieve success in any medical intervention as patients view their ‘non-adherent’ behavior as a matter of a self regulating process aiming at achieving autonomy as an individual self. Any patient care practice aiming to be patient-centered needs to account for the patient’s expertise in self-care. The non-adherence discourse goes against such practice as it underestimates the ability of the patient to care for himself or herself. It disregards patient’s autonomy (Conrad, 1998), therefore, threatening the success of any therapy as it does not take into consideration the patient’s perception and understanding of his or her illness. Thus, pharmaceutical care practice and medication management services attempt to bring this patient-oriented care to individuals who take medications chronically.

Since adherence to clinicians’ orders is the *sine qua non* condition for the success of antiretroviral therapy, any deviation from that predicts therapeutic failure. From a biomedical standpoint, there is little disagreement with such claim. Nevertheless, from a sociological standpoint and from the perspective of a patient-centered practice such as pharmaceutical care, it raises important questions. It is also important to account for pragmatism in health care. There is no way to ensure patients will be 100% adherent to drug therapy and to morally judge non-adherent patients as deviants is potentially threatening to the therapeutic relationship between clinician and patient.

Studies on treatment compliance suggest that at least 30% of patients do not take their medicines as indicated (Conrad, 1987). The numbers for long-term compliance are even worse, with studies showing an average of 50% of patients not complying with prescribed treatments (Conrad, 1987; WHO, 2003).

Most patients evaluate the efficacy of their treatment by analyzing the expected outcomes of a given treatment (Conrad, 1987). In HIV/AIDS, such outcomes are mainly laboratory tests on viral load and CD4 cells count. The non-adherent behavior is shown in the literature as a self-regulation phenomenon (Conrad, 1987; Shoemaker & Ramalho de Oliveira, 2008; Ramalho de Oliveira et al., 2012) in which patients may exert control over their drug therapy. In the context of HIV/AIDS, as discussed above, patients encounter several challenges that might hinder them from being 100% adherent to their medication regimens such as the stigma and emotional distress associated with this condition and the side effects of the medications. Also, it must be stated that from the clinician's perspective, success of drug therapy in HIV/AIDS is measured by biochemical measures, mainly according to the results of laboratory tests on viral load, CD4 cells count as well as lack of clinical symptoms. On the other hand, from the patient perspective, besides the CD4 and viral load indicators, the experience of illness and its treatment are highly considered when it comes to evaluating drug treatment. Conrad (1987) argues that such discrepancies should be addressed from a broader perspective in which clinicians take into consideration patients' perspectives and experiences in order to achieve more positive results. In pharmaceutical care practice, the biochemical and the sociological aspects of treatment need to be balanced in order to ensure the success of

any given drug therapy. The perspective of the patient, the most active player in drug therapy is a key issue on this matter.

In pharmaceutical care, during the assessment of the patient's drug therapy, the pharmacist goes beyond the clinical evaluation of the antiretroviral therapy. The pharmacist's goal should be to improve the patient's experiences with his or her medications, making sure that the patient's story is well understood and that all his expectations and concerns are taken into consideration when designing the care plan.

The medication and illness experience

There is an extensive array of literature discussing the meanings of medications for patients living with specific conditions and taking specific classes of medications (Adams et al., 1997; Rogers et al., 1998; Knudsen et al., 2002; Stephens et al., 2002; Visawanathan & Lambert, 2005). In the context of pharmaceutical care, Cipolle, Strand and Morley coined the term medication experience to describe the experience patients have with medications in their lives. They defined medication experience a "the sum of all the events a patient has in his/her lifetime that involve drug therapy" (Cipolle et al., 2004). The medication experience is a central piece of the pharmaceutical care practice as it involves the patient's experiences of taking medication in their lifetime and the meanings the patient gives to his/her treatment. According to Cipolle et al. (2004), the concept has three dimensions: the medication history, the current medication record and the patient's description of the medication experience. Nonetheless, this research focuses

solely on the last one since the other two dimensions are pertinent to clinical aspects that must be assessed by the practitioner who takes care of the patient. While these two aspects are decisive to the development of the care plan, for the purpose of this research they are not relevant since the main focus of this investigation is on the concerns, understandings, attitudes, cultural and social aspects of the medication experience as perceived by those in use of medications.

Scholars such as Shoemaker and Ramalho de Oliveira (2008; 2012) have furthered looked and expanded the medication experience concept. They define the medication experience as “an individual’s subjective experience of taking a medication in his daily life.” That experience is not a one-time instance. Indeed it is influenced by present and past experiences and it may change overtime. The type of medication one is taking and the health problem one has to live with also shapes it. They assert that: “The experience begins as an encounter with a chronic medication. It is an encounter that is given meaning before it happens and is often a reaction to the symbol that medication holds. The experience may include positive or negative bodily effects. The unremitting nature of a chronic medication often causes an individual to question the need for the medication. Subsequently, the individual may exert control by altering the way he takes the medication and often in part because of the gained expertise with the medication in his own body" (Shoemaker & Ramalho de Oliveira 2008).

As these authors suggest, the 'expertise' gained by the patient plays a key role on his therapy. Hence, this 'expertise' needs to be understood.

The patient's medication experience is very relevant within the context of patient-centered practices or in situations where the preferences, needs, and concerns of patients are claimed to be the main focus of the care provided. It is believed that the medication experiences will influence patient behaviors regarding medication taking. For instance, research conducted with Hispanic people living with HIV/AIDS (Sanchez, 2006) has shown that patients create their own rituals when taking medications. According to the author, the rituals are created as a way to deal with side effects of medications' use. It seems crucial to uncover these experiences from patients' stories and reflections on their treatments. Thus, with this gained knowledge, it is possible to build more effective medication management services that will address what is meaningful, important and concerning to patients themselves. In the context of people living with HIV, understanding the medication experience of these patients may be the key missing component to designing a patient-centered program that will lead to improved clinical outcomes and patient satisfaction with pharmacy services.

The medication experience as described by patients has a great value in pharmaceutical care practice as well as in the whole context of health care. Recently, research conducted with experienced pharmacists in a medication therapy management program in Minnesota suggests that the patient's medication experience can be at the root cause of drug therapy problems (Shoemaker et al., 2011; Ramalho de Oliveira et al., 2012). Thus, by understanding patients' medication experiences the MTM pharmacist is able to intervene to improve these experiences and prevent or resolve drug therapy problems. Furthermore, listening to patients' stories has a great value for those who take

care of someone as well as to those who are taken care of. As suggested by Kleinman (1988), talking to patients can have therapeutic value as it helps those in need to order their suffering experience. The same can be true for the patient's medication experience. In addition, it highlights the difference between what is experienced by patients from what is perceived by practitioners in their focus on the disease (Kleinman 1988).

Human beings tend to seek for meaning in their everyday lives. They tend to associate things in order to recreate a logical sense to life. People with chronic diseases tend to seek and find meanings to their new conditions and experiences in order to rearrange their life balance. Their social as well as personal lives are suddenly disrupted as a result of a new diagnosis. The use of narratives can help to position these meanings in a logical way, providing some sense to this new life condition. Kleinman (1988) argues in his pioneering book that illness narratives can indeed have therapeutic value as they help to order the illness experience of individuals.

Why is the study of narratives about medication important? Bissell and colleagues (2006) address this question suggesting different levels at which to look. In clinical levels, the authors claim that there is clinical significance in people's narratives to the point that individuals provide valuable information so health care providers can "understand where the story is situated and how it affects the person's outlook and their orientation towards treatment". The authors go further implying that the stories are constructed through the intersection of various players and their roles are "affected by social and cultural factors such as gender, ethnicity, age or social class" (Bissell et al., 2006). These narratives may affect the way health care is organized and consequently

delivered. As such, it is important to closely look at those experiences. To quote Bissell, “when employed in conjunction with the biomedical model of health and illness, narrative analysis can enhance both the practitioner’s and the patient’s understanding of the impact of an illness and its treatment upon the individual’s life” (Bissell et al., 2006). It suggests that the medication experience is embedded in the medication narratives proclaimed by Bissell. It plays a pivotal role in the illness narratives as most medical interventions, particularly in HIV/AIDS, involve the use of chemical agents to treat the chronic condition.

Bissell argues that the medication narratives are useful in “illuminating [ones] self-identity and biographical repair in times of change such as acute or chronic illness” (Bissell et al., 2006). It may be pertinent to the stories of patients with HIV in times of change in which one meets the standards for initiating drug therapy to fight HIV. The change in this case is from not using medications at all to forming a close relationship to it on a daily basis. Another dimension may be added when a change from a previous line of treatment is required due to virological and/or clinical failure of a previous line. The narratives gain a momentum in the clinical care as the patient’s stories need to be rearranged.

The medication experience in the form of narratives bring to the attention of the health care providers the personal, social and experiential dimensions that either directly or indirectly impact the relationship that the patient has with his/her medication on a daily basis. Such experiences impact the patient’s attitudes and behaviors, which extrapolates the rational knowledge provided by the biomedical model. The medication narratives and

the medication experience may have a key importance in the understanding of why some people are highly compliant to the prescribed treatment while some others are not. This is particularly important in the context of HIV/AIDS as a high level of adherence is expected.

Previous studies have shown that daily management of HIV drug therapy has problems (Meystre-Agustoni et al., 2000) associated with its management. It includes life limitations imposed by HIV treatment and its side effects (Meystre-Agustoni 2000), which may be translated to the physical impact of treatment in both short and long term (Brashers et al., 1999). Meystre-Augustoni (2000) also claims the psychosocial impact of HIV/AIDS as the mere recognition that being under the use of anti-HIV drugs may place the HIV infected individual as someone socially rejected. Although this social rejection may not be directly linked to the use of HIV medications, the experience of using medications may somehow impact the individual's experience.

One cannot discuss the medication experience without examining the illness experience. Medications are a central piece in the treatment of most chronic conditions. In fact, medication can be claimed as the most used therapeutic intervention in the most common chronic conditions.

In the current biomedical model, understanding patients' illness narratives is regarded as something not important and most clinicians do not take it into consideration when caring for patients. However, many claim that it should be a core task of health practitioners (Kleinman 1988; Charon & Montello 2002; Charon 2006). Illness impacts individuals' lives in several ways. The social disruption of a chronic diagnosis impacts

one's life socially, geographically, and personally. The feeling of being disconnected is discussed in the literature. As such, individuals with chronic illness need to reconnect to their lives in order to find meaning on it. The term 'narrative reconstruction' was coined to recount the ways that people use to reframe stories about themselves and their life history aiming to reorder their lives (Williams, 1984).

Illness experience cannot be entirely explained by biomedical models. The experience is closely attached to individuals' perceptions and narratives can help create some order in their new condition. The value of patients' narratives find support on Bury's argument that "patients' illness narratives, once silenced by a paternalistic if not overtly authoritarian medicine, suddenly find a new voice... Under all of these conditions it is not surprising to see illness narratives gaining greater attention once again" (Bury, 2001).

When one talks about a particular illness and considers its treatment, it should be clear that it requires changes in daily life. Activities that once were naturally done may need to be adjusted to the new condition. Medications can have a significant impact on someone's life, particularly their side effects. In HIV/AIDS, both the illness and the medication experience can be particularly intense, as there is an important stigma associated with this condition and the medications are known to cause overwhelming side effects. These effects require a life adjustment and may require additional drugs to manage the new condition.

In conclusion, considering the importance of medication adherence for people living with HIV and the current state of pharmaceutical care practice and medication

therapy management services, it is the goal of this research to deeply understand the experiences of patients with HIV with their medications so that more effective and patient-centered MTM services practices can be developed and delivered. This research aims to fill the gap on what is currently understood about the medication experience of people living with HIV/AIDS and their perception of the disease and medication use in the context of pharmaceutical care practice.

The literature on HIV/AIDS and medication use proclaim the need for more patient-centered and individualized care. Nevertheless, these same studies do not have pharmaceutical care philosophy and practice as the context in which to better understand and improve patients' medication experiences. Understanding and addressing the medication experience can be the most appropriate way to meet the medication needs of patients in a patient-centered manner. This research proposed to construct a theoretical framework for medication experiences of patients living with HIV/AIDS in the context of pharmaceutical care practice. Its aim was to understand the medication experience from patients' perspective. The intersection of pharmaceutical care and HIV/AIDS care seems to be a perfect environment to work towards a standard of care for people living with HIV/AIDS.

Chapter 3: Methodology and methods

This chapter presents the design and the methodological trajectory that led to the construction of the main results of this study. Each section of this chapter describes a different aspect of the research process designed to answer the research question, which was especially focused on the development of a theoretical framework of the medication experience of people living with HIV/AIDS.

The methodology of investigation

This study used grounded theory as the methodology of investigation. As a qualitative methodology, grounded theory attempts to propose theories generated from a comprehensive analysis of patterns, themes, and common categories obtained in observational data (Corbin & Strauss, 2008). The main objective of a Grounded Theory study is to provide an understanding of a phenomenon intrinsically related with the context of individuals living the phenomenon (Creswell, 1998). The explanations proposed by grounded theory studies are generative rather than definitive theories (Daly, 2007, p. 102). Thus, grounded theory studies are primarily exploratory as it intends to propose an explanation of the phenomenon being studied.

As a qualitative methodology, grounded theory studies are likely to contribute to knowledge building that arises from "the interaction of researchers with those whom they

research" (Gilgun, 2010). In this study, the investigation was conducted through interactions of the researcher with people living with HIV/AIDS. The medication experience was the phenomenon being investigated. Grounded theory is suitable to this type of study as it aims to show multiple meanings and multiple dimensions of a human phenomenon (Gilgun, 2010). Moreover, it is "well suited to asking questions about sensitive topics that are complex or changeable"(Daly, 2007). Grounded theory is also appropriate to match outcomes and clinical practice as it embodies patients' perspectives in the inquiry (Daly, 2007). In this sense, this was an appropriate methodology for this study as it aimed at offering meaningful direction for further action of practitioners taking care of people using medications to treat HIV/AIDS.

In this research, the phenomenon of study was the HIV medication experience and its relevance to the patient. Additionally, these experiences were analyzed and interpreted in the context of pharmaceutical care practice.

Grounded theory studies do not use an already existing theory as a starting point for the investigation (Creswell, 1998). Thus, the researcher started this study with an open stance towards the data and no explicit prior theoretical assumptions about what it is like for patients to use medications to treat HIV/AIDS. In other words, the medication experiences of people living with HIV/AIDS in this study are explained through the interpretation of patient's narratives. The narratives were collected through one-to-one in-depth interviews with individuals diagnosed with HIV/AIDS using antiretroviral drugs. The researcher interviewed all participants at least twice during a period of 6 months. In addition to the interviews, all participants were given a notebook and asked to keep a

journal where they could write about their experiences, feelings and thoughts related to their daily medication use. The journals contain the participants' reflections about medication use on a regular basis. The journals were shared with the researcher in the last interview.

The ultimate goal of this study was to propose a theoretical model that can explain the medication experience of people living with HIV/AIDS. Ultimately, the model intends to help the practitioner in the patient care process. The theoretical model was built through the investigation of the relationship of people living with HIV with their drug therapy. The understanding of the medication experience is “grounded in the data” rather than attempted to fit into any preexisting theory of the medication experience. The analysis of the data generated the proposed theoretical framework of the medication experience of people living with HIV/AIDS.

Therefore, for the reasons aforementioned, grounded theory is well suited for addressing the research aims. Moreover, the methodology is appropriate for the investigation and understanding of the medication experience that might be utilized by practitioners providing medication management to patients living with HIV/AIDS. In addition, it may also suggest ways of managing patients in use of medications beyond the diagnosis of HIV.

Sampling criteria

Purposeful sampling was the criteria initially applied to select participants. In purposeful sampling, participants are selected among those who are able to generate information about the phenomenon being studied (Morse, 1991). Thus, in this study, participants were recruited based on their willingness to share their experiences with taking antiretroviral medications to fight HIV infection. The participants were selected among patients who regularly fill their prescriptions for anti-HIV medications at a pharmacy located in the Twin Cities Metro Area.

In this study, the participants were chosen among those able to contribute to the understanding of medication experience because they are using anti-HIV medications. The sampling criteria for this study included adult participants who were HIV infected and had indication for HIV drug therapy. Additional inclusion criteria were that participants should be able to speak, read, and write in English and that their functional cognitive capacity should be preserved. The exclusion criteria included patients not being able to read, write, or speak English, or potential participants meeting inclusion criteria having been diagnosed with schizophrenia, psychotic disorders, or mental retardation.

Following the approach of grounded theory, in this study data analysis started as soon as the first participant was interviewed. Major scholars in grounded theory methodology support this process. After the first interview, theoretical sampling became the main strategy for sampling participants. Theoretical sampling has the intention of developing the properties of the developing categories (Charmaz, 2006). The purpose of theoretical sampling is to collect data that can generate theories. With that in mind, participants who were able to provide information about the phenomenon under

investigation were sampled. The rationale was to collect data in order to improve and elaborate the categories that form the theory (Charmaz, 2006), sampling for experiences rather than sampling individuals. In other words, the first interviews were analyzed and the data generated, or the emerging themes, served as the basis for further investigation. Over time the properties of each theme were refined until no new properties emerged. In this study, the researcher believes that the meanings of some of the emergent themes were not fully explored or exhausted due to the limitations in participants' recruitment.

As noted above, participants in this study were recruited from a retail pharmacy that is part of a health delivery system in the Minneapolis-St Paul area. The pharmacy is associated with an infectious disease clinic. However, it should be stated that the pharmacy is not exclusively used by people living with HIV/AIDS. Rather, it is a regular pharmacy that dispenses a wide variety of medicines, including HIV drugs. The pharmacy has a specific pharmacist assigned to work with people using anti HIV drugs and a pharmacy technician assists her. They both work exclusively with people living with HIV/AIDS. Both the pharmacist and the technician were the first contact with potential participants. Potential participants were informed about the study. If an individual agreed to participate or to listen to more details about the research project, they were invited to contact the principal investigator, the present author. The potential participant was selected according to the discretion of the pharmacist, who had knowledge of the research purpose.

Qualitative studies do not rely on large sample sizes to claim validity for the concepts generated. Sample size in qualitative studies has a different meaning than in

quantitative studies. The unity of analysis in grounded theory is the concept generated by data analysis. Thus, sample size in grounded theory studies is estimation rather than a requirement. Morse and Field (1995) suggest a minimum of 30 participants for a grounded theory study, even though this claim does not find support either in the original or subsequent work of Strauss and Glaser (1967). Also, contemporary prolific qualitative authors such as Charmaz (2006) and Denzin & Lincoln (2000) do not urge a minimal sample size for grounded theory studies. In the literature, sample sizes for studies using grounded theory methodology may vary widely from as low as 13 participants (Weymiller, 2009) to as many as 30 participants (Morse & Field, 1995). Thus, this study followed the core foundation of theoretical sampling and its methods to reach data saturation. Even though a sample size of 30 participants was initially proposed, this study included 9 participants.

Recruitment did not accomplish the initial goal of 30 participants in the study. The reasons for the small sample size were not extensively investigated. Nevertheless, based on the conversations with the participants and their journals, there seems to be a relationship between the small sample size and the topic of this investigation.

Some of the participants suggested some level of discomfort on talking about their HIV experience with someone they were not familiar with. Nonetheless, what seems to be most difficult was to bring back memories and feelings from the time when they discovered about their HIV status. Johnny illustrates that on his journal, saying that the first interview “really brought back a lot of memories and emotions.” He emphasizes that such memories are not only related to the illness itself. Rather, it goes beyond that

involving the complexities of a relationship that did not work as intended and has caused him much suffering.

For Kelly, the first interview occurred exactly 12 years after the day she received a positive test for HIV. She had forgotten the day but the interview reminded her about that terrible day. After our first interview, she writes on her journal “I didn’t realize today made 12 years of living with this infection...honestly, it felt good to forget what today was. My interview brought up a lot of mixed emotions and thoughts. But I bounced back as I always do.”

As Kelly, Johnny, and others reflect on their interviews, it seems clear to me that the difficulty of discussing a sensible topic may have contributed to a low number of participants.

Setting

The study setting is the pharmacy in which research participants fill their prescriptions for antiretroviral medicines. The pharmacy is part of a large health care delivery system in Minnesota. The pharmacy dispenses antiretroviral medications among all other types of medicines. Nevertheless, there is a pharmacist and a technician exclusively assigned to work with people living with HIV/AIDS. That means that the pharmacist knew potential participants. The pharmacist is currently in the process of building her own pharmaceutical care practice. Indeed, she is transitioning from being a dispensing pharmacist to becoming a pharmaceutical care practitioner.

This setting dispenses antiretroviral medications to approximately 300 patients. The majority of the patients assisted in the pharmacy receive their medications at home. The drug supply is shipped once a month to the patient's home. The pharmacy is not located in the same physical space as the HIV clinic. Despite being part of the same health care system, they work independently. It means that a patient may use the clinic but not the pharmacy. Conversely, a patient may fill his prescription in the pharmacy but might see the provider in a different clinic.

Since the participants were mainly recruited with the support of the pharmacist, the research setting is considered to be the pharmacy.

Recruitment

The participants in this study were initially contacted by the pharmacy personnel supporting the researcher. A potential participant was identified and informed about the study. The pharmacy staff handed the information sheet approved by the Institutional Review Board at the University of Minnesota to each potential participant identified by them. The information sheet - Appendix C - contained a summary of the research as well as the researcher's contact information. The staff did not keep track of those patients who called the researcher. The decision of whether to contact the researcher or not was solely made by each potential participant.

Once the potential participant received the information sheet, those who were willing to participate called the researcher. In common agreement between the two

parties, an interview was scheduled according to the convenience of both. The researcher had no previous information about potential participants before he or she contacted him. In addition to the research flyer that was handed to potential participants, flyers were also placed on the community boards surrounding the infectious disease clinic as well as in the wallboard located inside the clinic itself.

Approximately five months after the authorization to initiate the study was granted by the IRB, it was decided that the recruitment process was not as successful as initially anticipated. Therefore, other locations were identified as potentially useful to recruit participants. A change in the research protocol was submitted to the Institutional Review Board. The request was for authorization to allow the distribution of research flyers to potential participants attended by organizations dealing with people living with HIV/AIDS. The main target was the Minnesota AIDS Project — MAP. The Aliveness Project was also considered. The Institutional Review Board granted the authorization. Thus, the researcher contacted the Minnesota AIDS Project to request their support in recruiting participants. Unfortunately, the request was not addressed attended by the Minnesota AIDS Project. The reason why is not clear to the researcher. In fact, it was not denied. Rather, the researcher was informed that the request was being processed. Nevertheless, a final answer has never been delivered to the researcher. Thus, the recruitment was restricted to the initially proposed setting.

The participants living with HIV/AIDS

The participants in this study are adults living with HIV/AIDS. The participants are nine in number. Eight are men. This study was conducted from April 2011 to April 2012. During this period all participants were living in Minnesota. The participants are Felix, Donovan, Jack, Johnny, Beni, Sergio, Kelly, Noah, and Billy (participants' fictitious names). The youngest patient is 27 years old and the oldest 70 years old. All participants are Americans. Three are African Americans. Six are homosexuals. The majority of the participants have at least a college degree and all have completed high school. One participant completed graduate school at the master's level. One is currently enrolled in graduate school. One participant is unemployed. Four participants live alone in their homes, two live with at least one child, two others live with parents, and one lives with roommates. All nine participants have means to survive and there is no one living with government aid.

It is important to say that the recruitment process was not as successful as anticipated. The initial sample was intended to reach 30 participants. Nevertheless, a sample size of nine participants was reached. There were three potential participants who initially agreed to participate in this study. Nonetheless, before the first meeting was scheduled they rescinded their decision to participate.

Despite the small sample size, each individual shared rich and thoughtful stories through multiple interviews and personal journals/diaries that were shared with the researcher. These stories reflect their experiences and their understandings of their experiences contributing to an in-depth exploration of the major themes discussed in this study.

Participants were not classified according to their diagnoses for this study. No distinction between the diagnoses of AIDS and being HIV positive was made. In fact, most participants were not fully aware of their condition. Only one participant acknowledges having “full blown AIDS.” The other eight participants either are living with HIV or do not know whether they have AIDS or not. For this reason, in this study HIV infection and AIDS are cited as HIV/AIDS.

Felix

Felix is the first participant recruited for this study. He is a white middle class American. Felix is 70 years old, divorced, has three children and five grandchildren. He does not work anymore. He owned a retail business until he retired.

Felix lives alone in a small and comfortable apartment located in the Minneapolis metro area. Interviews with Felix were conducted in his apartment. He lives near to one of his sons. Felix sees the proximity of a family member as a very positive thing. Felix seems to be a lonely person. He does not have many friends. His social life is restricted to eventual dinners with his son and daughter-in-law. Felix enjoys life around his family. He celebrates the opportunity to participate in his grandchildren’s lives.

Felix is legally blind. He has no vision in one of his eyes while he has partial vision in the other. Felix looks healthy. He has an athletic build. He does not show any signs of any disease.

Felix does not know how he acquired HIV. When he discovered his HIV status, in 2009, he did not have a sexual partner to inform about the situation. He says:

“There was no one to tell. There was not. I had no sexual partners to share the information with. The strangest (part) of it was (that) I probably hadn’t had sex since 1973.”

He found out about his HIV by accident, after a series of health problems he was dealing with after a car accident. At the time, he was living in the south of the United States and was already retired. His health condition was very precarious. Thus, he moved back to Minnesota in order to be nearer to his son. He lived with his son and family for a few months, and then decided to live by himself when he recovered from his health complications. Felix is a very polite man with good manners. His home is very well organized and clean.

The HIV drug therapy impacts Felix’s life to a great extent. He dislikes medications. He avoided taking any kind of pills, “not even taking an aspirin for a headache.” For someone like him, the commitment required by HIV drug therapy became a burden. Now Felix is used to the act of taking daily pills.

The HIV medications make Felix more emotional, as he states:

“I really, I found that with the meds that I’m taking that I’m much more emotional. I’ve got no memory of reacting emotionally to a known situation until (the) last couple of years.”

Donovan

Donovan is an African American living with HIV/AIDS. He is 40 years old.

Donovan is a law student. He looks like a stereotypical rap singer. Despite his mother's advice to wear a suit, he prefers to wear baggy clothes and tennis shoes. He argues with his mom "Mom, I'm six foot two. I'm a 130, 40 pounds and you want me to wear a suit? I'll look like a scarecrow." Donovan is intellectually smart and thoughtful. He likes to read and he expresses his ideas eloquently. Donovan's parents are health care professionals. His mother works as a nurse while his father is a physician. Having parents in the medical field did not prevent Donovan from acquiring HIV. Donovan has been on HIV drug therapy since the year of 2003. At that time he had a grand mal seizure and was rushed to the hospital. The physicians suspected an underlying condition for the unexpected seizure. Thus, they suggested an HIV test. The result was positive. Donovan says, "that's when I found out that I considered not (having) HIV, but full blown AIDS." His viral load was extremely high. Conversely, CD4 cells were low.

Physically, Donovan looks younger than his age may suggest. This impression can be from the way he dresses. Donovan is a tall man. His height is 6'2". At the time of his diagnoses, his weight was no more than 140 pounds. Today he looks healthy.

Besides major weight loss, Donovan had no other symptoms at the time of his diagnosis. He had no suspicions of being infected by HIV. Being in denial may have prevented him from looking at the weight loss and occasional colds as something more than the usual.

Donovan does not blame any particular individual for his HIV infection other than himself. He was probably infected 10 to 12 years prior to his diagnosis. He does not feel guilty or punish himself. As he says, “I had multiple partners. I was a young man. I guess I was probably very promiscuous.”

Donovan wants to give something back to society. He considers himself lucky to be alive after being sick. He participates in clinical trials aiming to help future generations with more effective HIV drug therapies. Thus, he claims to be extremely compliant to physicians’ orders. This includes 100% adherence to HIV medications.

Jack

Jack is a 41-year-old white male Minnesotan. He looks younger than his age.

Jack got his positive test of HIV in June of 2007. At that time, he had recently finished graduate school and had plans to move to Canada with his partner. His plans were abruptly interrupted by the positive test for HIV.

Jack works for a large company in Minnesota. He enjoys working at the company he is currently at but complains about frequent travels he has to make. He claims constant travels as something “disruptive.” When asked why, he says that besides being away from his dog, “it is hard for taking my meds.” His boss was supportive when he was told about Jack’s health condition a few years ago.

Jack claims to be adherent to his prescribed medications. He is currently taking the one-pill-per-day Atripla®. Jack seems to be a reflective person. Although he made the

decision to start the treatment to HIV when he got a diagnosis, he is still concerned about possible side effects in the long term. Besides the common side effects of Atripla® such as nightmares, night sweats and dizziness, Jack is more concerned “especially the liver and the kidney type, and I think is my liver problems that could occur down the road.” He shows some signs of regret of the decision made in the past about initiating the HIV drug therapy. He explains:

“I could go 10 years if my body reacts good and fights the virus. My body would naturally fight the virus. So my CD4 counts would go up and my viral load would go down naturally. Well, I could not need a pill for 10 years. That’s 10 years without taking the pill causing damage to my body. Without having any side-effects, right?”

Nevertheless, Jack continues, “but I was...like I said you before, I just didn't trust my body to react that way.”

Johnny

In 1995, Johnny (JS) received the result of his HIV test. It was positive for HIV-1. He received the devastating news as a shock since he was not really expecting a positive result. The exam for him was intended to make sure that things were fine with him. The devastating news came a few days before Christmas. His prognosis was not exactly as good as the person who handled the results of his test assured. Johnny was told that he would have one more Christmas so it would be better to enjoy what would probably be his last one. If he was lucky he might have two more.

Johnny did not take for granted the prognosis handed to him. He decided to take over his disease and find a way to deal with that. It has been over 21 years since Johnny cheated death and he looks healthy and positive towards his future. He has not developed AIDS according to his own accounts. Besides some side effects as a result of his anti retroviral therapy plus other drugs to treat depression and cholesterol, he has no symptoms of AIDS whatsoever. When asked about his illness symptoms he states that “everything is due to (the) side effects of medication.” Besides that, he considers himself a healthy man.

He complains about the side effects of his drug regimen, particularly lipodystrophy, which has given him some weight gain. He does not like the fat accumulation in his jaws and abdomen, though he considers himself a lucky guy for not having more complicated drug related problems.

Johnny is from a small rural town located in Northern Minnesota. He has tried several different regimens and seems to be comfortable with the current one. He considers his regimen easy to manage as he takes three pills once a day. Besides his antiretroviral medicines, Johnny also takes a few extra pills every day. Before being diagnosed with HIV he was already taking antidepressants and had added one more drug to combat high cholesterol.

He switched pharmacies in search of a better service since the one located near to his home often fails to meet his drug needs. He thought that he was the only person with HIV in the neighborhood and despite that, the pharmacy was frequently short on his

monthly supplies. He wanted something more personal so he ended up in the research site pharmacy, which he still frequents.

Beni

Beni is a 51-year-old white male. He defines himself as a “strong, powerful, responsible, loving, nurturing male, man, adult.”

Beni works with interior design and looks a little overweight. His voice denotes confidence and his ideas are very articulated. Although it was not directly asked, Beni states that he is homosexual. If he does not mention that, one would not guess it. According to his own words, he is “proud of what [he is].” He considers life as a journey and HIV is just a “part of the journey.”

Beni can see some positive aspects of being infected by HIV. He does not praise the virus but sees it as he says “part of the piece that got me to where I am.”

He articulates his ideas in a very eloquent manner and blames the religion and the “white supremacy” for prejudice against homosexuals. It seems to bother him as a person and his relationship with his family is somehow affected by such ideas. He sees such prejudice as a problem for people infected by HIV and a complication factor for something that is already difficult.

He did not have help when he started his drug therapy to fight HIV. He has figured that out by himself and seems to understand how his drug therapy works. Beni

has other health issues besides HIV. He has heart problems and currently takes 12 tablets per day. For him, HIV treatment is a small piece of his drug therapy.

Sergio

Sergio is a 50-year-old white man. He looks younger than his age suggests.

For the interview he showed up elegantly dressed. His voice tone is calm and he looks peaceful and relaxed. When he found out about his HIV status, Sergio was forced to face his philosophy of life. He defines himself as a Buddhist who does not believe in western medicine, despite his college training in science. He prefers to think that a healthy diet is the key factor for combating any health imbalance. Rather than taking medications, Sergio prefers to use natural substances before succumbing to synthesized chemical agents.

Sergio is a gay male. He is soft spoken with educated manners. He has three adopted children. Alone, he did the adoption process and raised all the kids. They are from overseas. Sergio claims to be raised in a very progressive family that has the tradition to adopt foreigners.

Being raised in a family open to differences is seen as helpful to cope with the HIV infection. His family gave him all the support he needed when he discovered the HIV infection.

Sergio grew up in Minnesota. He left the state when he went to college in New York. After graduating, he moved to San Francisco. A few years later he moved to

Europe before moving back to Minnesota. He works in an independent business. Also, he owns a small farm. Sergio is a polite man with a special love for the arts. He studied music in college. In the past, he transformed his love for art into work. He owned a small business that specialized in selling art.

Kelly

Kelly is a 34-year-old African American woman and a mother of two children. Kelly was pregnant when she discovered she was infected by HIV. She acquired the virus from her fiancé, the father of her second child. She never forgave the man. She claims to have been a faithful young girl at the time.

Kelly has a 15-year-old girl and an 11-year-old boy. They are the reason for taking the drug therapy. She says, “my children are the main reason why I’ve remained on the regimens so that I can be here to watch them grow. I believe back then they were still saying that the lifespan or whatever they were calling it, was like ten years.” Despite that, they do not know about her HIV condition. She argues that “they are not adult enough to handle the situation.” Moreover, she says, “I don’t want to put added stress on them, worrying if every time I get sick it’s related to that.” As most of the participants in this study, Kelly receives her medications through the mail. They are shipped to her home address every month. It requires extra effort to hide her condition from her children. She needs to hide the package as soon as it is delivered to circumvent her children’s curiosity. Besides that, their children have no reason to suspect Kelly’s health condition. Despite

being a little overweight, she does not have any sign suggesting a serious health condition. Her smile reinforces a healthy image. The secret is kept as long as she continues to show overall good health. Her HIV infection did not evolve to the AIDS disease.

Currently, Kelly works in two different jobs. Besides her full time job as an administrative assistant in a large company in the Minneapolis area, she recently began a part time job 3 nights a week. She complains of being tired lately. “It is because of my new job”, she says.

Kelly was very emotional during the two interviews. It is hard to talk about her illness and how it changed her life. Her eyes got full of tears when she talked about the time she got the positive test for HIV infection. It is like it was yesterday she says:

“...like it just happened yesterday. If I think about it I can describe to you how the room was set up, what I was wearing, what the doctor had on and everything. It is not like you go over the years and you forget things. That’s one thing that nothing has left my mind of the image of that day, nothing at all. That’s why I say that it’s embedded. I’ll never forget it.”

For Kelly, yesterday was over a decade ago, in the year 1999.

Noah

Noah is a 27 years old white male. He is nearly finished with graduate school at the Masters' level in urban planning. Noah does not have a formal regular job. He says that graduate school consumes most of his time. Noah grew up in Minnesota; nevertheless, when asked where he is from, he says "I'm from a lot of places". His family still lives in the state. Noah lived in Chicago and some cities in the state of California. He came back to Minnesota about eight months ago in order to collect data for his academic research. Noah is a "people person." He likes to work with people and do projects in collaboration with them.

Noah has been a student for most of his adult life. For that reason, he says, "I've never had a full time job." Consequently, as a part time employee, he works seasonally. Noah does not have health care insurance through his employers.

Noah tries to keep a healthy life style. He rides a bike to school, home, and work all the time, even during the winter. Noah has a tall and thin complexion. He is a single homosexual man.

Noah considers himself adherent to his prescribed drugs. Sometimes, he says, "doses are missed." The journal he kept between the two interviews shows lapses on drug adherence. A few doses were either missed or taken with more than the recommended 24-hour interval between doses. The drug regimen Noah is on may be considered the easiest one in terms of drug schedule. The regimen is taken once a day at bedtime, but Noah has difficulties keeping consistent with his drug taking. Bedtime is not a constant in Noah's life style. He has a busy social life. In order to avoid missing doses, Noah keeps a glass of water on his nightstand. Thus, every night the cup is there. In case the glass is

full of water, it means that the pill was not taken. If half empty, the drug was indeed taken.

Noah's experiences with living in other states brought interesting perspectives to this study. He has been dealing with government insurance in at least three different states — Illinois, California, and Minnesota. According to him, Minnesota is the worst among the three. The paper work required to receive medications is more bureaucratic and time consuming. He complains about not being able to move to different places before all paper work is done. The risk of being out of medication is high as drugs are dispensed for a one month period, while the paper work takes longer than that.

Billy

Billy is a 32 years old African American male. He is currently unemployed. His dream is to become a music producer. His plan is to start school soon.

Billy is very close to his family, particularly to his mother. In fact, he claims his mom as the reason for being adherent to his HIV treatment. Billy celebrates his family support, especially when he disclosed his HIV status. During the two interviews, Billy shows emotion when talking about his mother. He says:

“I hated hearing stories about that, but then I’m sitting here looking at myself and I’m like damn here I am, all my family’s supporting me and I’m sitting here isolating them. I’m pushing them away. And most people would love to have their mother, or their father, or their family members support them and some don’t even have that. I’m lucky to even have that. So that’s what kind of made me just

realize that I have it good than what most people have. So that's what kind of just made me reach out and just say look mom I'm sorry. I was just a bullhead at times but I'm here. And it's been like that ever since."

Anti-HIV treatment was prescribed to Billy right after receiving the positive HIV test. He did not accept it right away. For years Billy was on and off medications. During that period, Billy isolated himself from his family. He justifies his behavior for being in a "denial mode." He did not accept the fact of being infected with HIV. Therefore, it was easier to run away from everyone. He regrets the behavior.

Billy discovered his HIV infection in the summer of the year 2000. It is more than a decade ago. Nevertheless, he has been on medications only for over a year. For him, side effects are the reason for not taking the prescribed medications. In addition to the side effects, complex schedules undermined his commitment to HIV drug therapy.

Billy declares that constant hospitalizations are one of the main reasons for him to finally accept his drug therapy. Meanwhile, he felt guilty for seeing his mother suffering because of his poor health. He decided to take care of his health. It was a turning point in Billy's life. Since that promise, over a year ago, he says that he has never missed a single dose of his medications. He does not recollect the names of the medicines he is on, but they are "not too bad." According to him, the current regimen has a good schedule that fits his life style:

"I finally found a regimen the kind that I'm going to stick to, so I found it more easy. I take pills twice a day so it's not too bad - in the morning and at night. So that's a good schedule; once when I wake up and then once when I go to bed. I just pop them in and there's no side effects anymore."

However, Billy does not look like a healthy person. He has very dry skin. His neck and hands appear to have fish scales. He is a thin man with a very fragile appearance.

Data collection

Data was collected primarily through in-depth unstructured interviews with people living with HIV/AIDS. Each participant was intended to be interviewed twice. Two participants did not show up for the second interview. Interviews ranged from forty-five minutes to two hours long. A room located at the University of Minnesota campus was used for the majority of the interviews. Two participants suggested alternative locations for the second interview. Hence, a coffee house served as the location for the second interview with two different participants. One participant suggested his home as the place to be interviewed. The reason for that relies on the fact that the participant claimed difficulty to find transportation. The principal investigator conducted all interviews.

Besides the two in-depth interviews, each participant received a notebook with oral instructions to keep a log of their experiences. The notebook was intended to collect reflections, concerns, and feelings towards daily medication use. The journal had the intention of serving as an alternative method for collecting data. It accommodated the participants who might feel more comfortable writing than speaking. All participants

received a notebook. Four participants did not return the journal. Despite not being the primary source of data collection, the journal provided very interesting insights for the construction of the results of this study.

In addition to the in-depth interviews and the participant journal reflections, the researcher field notes were also a source of data collection and analysis. Reflections of field observations and regular visits to the pharmacy were used as data collection. The field notes are referred in this thesis as researcher reflections. These reflections can be situated in the concept known as sensitivity. Corbin and Strauss (2008 p.32) defines sensitivity as the researcher “having insight, being tuned in to, being able to pick up on relevant issues, events, and happenings in data. It means being able to present the view of participants and taking the role of the other through immersion in data.” Sensitivity, therefore, can be placed as the antithesis of objectivity.

Data analysis

Data analysis occurred simultaneously with data collection and started as soon as the first participant was interviewed. Preliminary analysis was made after each interview was conducted. This preliminary analysis was used as a guide for the follow-up interviews as well as for the theory construction.

Each interview was transcribed and analyzed by the principal investigator. The computer software MAXQDA® was utilized to help in the data analysis. The software

helped in the identification of themes that were emerging during the interview process, thus, forming the concepts that were the base for categories.

The theory was *constructed* after the data was analyzed. Rather testing a priori thesis, this research intends to construct knowledge. The knowledge construction finds support in grounded theory studies and the perception that “theories are constructed by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and/or lives, both to the researcher and themselves” (Corbin and Strauss, 2008. p. 10). Thus, in theory building, the stories that emerge from those who experience any given phenomenon can have different outcomes, even though the data source is the same. In order to reach the point in which the researcher “felt right” (Corbin and Strauss, 2008. p. 47) about the result, the researcher immersed himself intensively in the data as a method to reach the intended result. Feeling right about the result is a consequence of the constant immersion in the data and the essence is finally achieved after the interpretation of data feels logically reasonable.

The interviews were read multiple times and analyzed for emergent themes or categories. Each interview was read several times so that the researcher could obtain an understanding of the whole. After a holistic understanding of the entire interview, the text was read again, sentence by sentence, in order to find the units of meaning throughout the text. These ‘pieces’ of texts were considered units of meaning because they assisted the researcher to answer the research questions and get a more in-depth understanding of the phenomenon under study: the medication experience of patients living with HIV/AIDS. Then, these units were further explored in order to find any associations and/or overlaps

between them. In this way, similar units of meaning were assembled to form the themes. The data were analyzed and categories were developed through observations regarding their relation with the following items as suggested by Kelle (2007. pp. 202): phenomena, causal conditions, context, intervening conditions, action and interactional strategies, and consequences.

Since hypotheses were not tested, the categories emerged from the data rather than being forced into previous theories (Kelle, 2007).

Ethical considerations

After successfully defending the research proposal and getting approval by the research committee, the research protocol was submitted to the Institutional Review Board (IRB) at the University of Minnesota. The IRB approved the study — Appendix B. A change in protocol was later requested. The same IRB conceded its approval — Appendix E. The change in protocol requested the authorization to post study flyers requesting participants in public areas.

All participants read and signed the consent form — Appendix D. A copy of the form was given to each participant while another one was stored by the researcher. After reading and discussing the consent form with the researcher, all participants granted authorization to participate in the study. Nonetheless, two participants did not show up for the second interview. The participants did not say no to the appointment. They simply did not show up for the appointment. After unsuccessful attempts to contact the two

participants, the researcher assumed that they did not want to meet once more. Thus, no further attempts were made to contact them.

All participants' names were changed to fictitious names and all the information that could be connected to a specific participant was deleted from the final write up.

Chapter 4: Results

This study aims at understanding the medication experience of people living with HIV/AIDS and its influence on medication taking behavior. The ultimate goal is to offer a fresh perspective on the relationship that patients with HIV/AIDS establish with their drug therapy. The relationship between patients and medications are discussed from the perspective of those in use of anti-HIV medications.

It is important to state that the results are entangled with the interpretation of the researcher. By interpretation the author means that the results are analyzed and understood in the context of patient-centered care and their implications to the practice of pharmaceutical care.

The main findings of the study are summarized in the theoretical model introduced in the beginning of this chapter. The model is called the *Influences on the Patient's Relationship with Medication in HIV Drug Therapy*. The proposed model is not conclusive. Rather, the model is a proposition to emphasize the important aspects influencing the patient's relationship with anti-HIV medications.

Influences on the Patient's Relationship with Medications in HIV Drug Therapy: A proposed Model

The theoretical model presented here summarizes the different aspects influencing the patient's relationship with medications. The conceptual model intends to illustrate the processes in which the patient with HIV may undergo during the course of the illness. It

portrays the challenges of medication use and the factors influencing the patient's decision making. The model is shown below followed by the explanation of its factors and the processes involved.

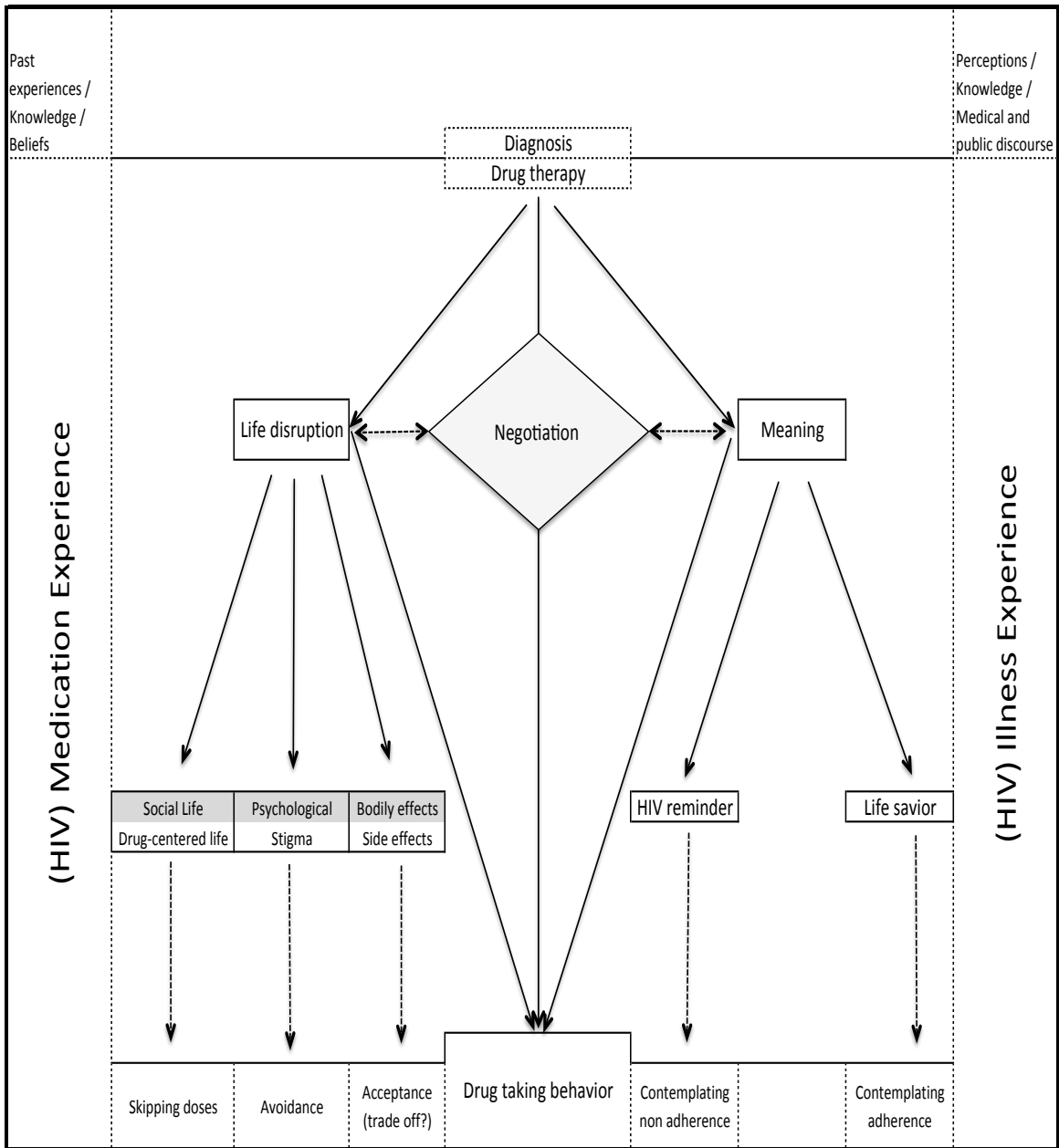


Figure 1: Influences on the Patient's Relationship with Medications in HIV Drug

Therapy: A proposed model.

The model is more abstract in the higher levels of interactions at the same time it is more detailed in the lower levels of interactions. The abstractness is related to stage one, which deals with the past experiences of the patient. In addition, stage one includes the patient's perceptions and knowledge about illness and use of medications. Also, the perceptions and experiences are not necessarily related to HIV/AIDS. It can be overall experiences with other illness that may have indirectly affected the current patient experience with his or her new diagnosis. It is discussed in the next sessions. The participants in this study discuss their experience with other illness conditions. Meanwhile, family member who have experienced a chronic condition other than HIV also represent an influence in the participant's own experience with HIV.

In the lower levels of the model, which I define as the stage two of the experience, there are specific aspects influencing the patient's drug taking behavior. In this stage, the model illustrates some particular elements affecting the patient's relationship with medications in HIV drug therapy.

As stated before, it should be emphasized that the model is not definitive but propositional. It aims at explaining the complexity of the relationship of patients with medications and how drug-taking behavior may be influenced by multiple factors.

Building upon experience: "I've been trained to be compliant"

Experience can be defined as a "direct, observational knowledge of the world" (Oxford, 2005). As such, experience is a knowledge built mainly through direct and

sensorial experience. Nevertheless, knowledge can also be built through indirect experiences. Therefore, people can learn about the world without necessarily living all possible experiences. Thus, it seems reasonable to claim that experience may be the result of both indirect as well as direct observations of the world. It can be sensorial or not.

In this study, the definition of experience includes both direct and indirect knowledge because that is how participants' experiences are constructed. In other words, experiences are built over time and find support on beliefs and perceptions of each individual. The theoretical model proposed in this study is constructed around the idea that both the medication experience as well as the illness experience begin before the patient receives the positive result on a HIV test. The past experiences influence current ones, which can be built on the foundation constructed in past experiences through direct observation of the experiences of loved ones such as family members and friends. Also, present experiences and behaviors can be a result of a public discourse on a particular theme and time. All developed perceptions, indirect experiences through others, and direct experiences come together to shape the person's lived experience of a particular phenomenon.

Thus, the first idea proposed in this model is that the HIV diagnosis occurs in an environment in which experiences already exist. The diagnosis is the inductor of what can be defined as the sensorial experience. The sensorial experience in this model is not necessarily related to symptoms of the HIV infection. That is not the case as most of the participants in this study discovered the HIV infection during the asymptomatic phase. Interestingly, the sensorial experience started being identified by patients after the HIV

diagnosis and with the beginning of the treatment. Then an array of symptoms and feelings started being associated with HIV-AIDS and with the side effects of HIV medications.

The diagnosis of HIV marks the transition in the patient's experience. The experience before the diagnosis is constructed on the observations of others in a similar condition. Also, the perception of the severity of the disease is constructed through observation of media discourse as well as medical discourse. For instance, Beni's experience with anti HIV medications was constructed through the observation of other people with HIV in use of zidovudine to treat the illness. He says "everyone that I knew that took the [zidovudine] medication died."

In the proposed model, the medication experience and the illness experience has two stages. The first stage occurs before the diagnosis and the prescription of drug therapy. Stage one is constructed through observations of actions or experiences related to living with HIV and taking medications. For instance, patients' experiences can be shaped by the use of medicines to treat a chronic condition other than HIV infection. The experience is also constructed with observations of loved ones in use of chronic medications. The same process happens with the illness experience. The patient's experience in stage one is constructed over time observing the news and public discourse on the health problem. Thus, stage one, in this study, represents the experiences of the participants before the formal diagnosis of HIV infection.

The transition of stages occurs after the diagnosis and the consequent prescription of drug therapy that occurs with all the participants in this study. The experiences brought

by the participants from stage one influence the experiences lived in stage two. For instance, in terms of being compliant with medications, Noah explains that his experiences with medications as a child have helped him to become compliant to the treatment. He says:

“What makes me compliant? Well, there is probably a few things. I was a medicated child. So as a kid I was taking medications that I didn’t really understand and I didn’t really feel like I needed them. But in this case [HIV infection], I know that I need them and I want them. So that behavior’s kind of inverted or reversed. But it’s still the idea right; I’m taking medication. I’ve been trained to do that as a child; I didn’t like doing that as a child but I knew how. Doesn’t mean I always did. But I knew how. And as an adult, that same behavior, or at least understanding how to be compliant with medication probably helps as an adult because I know how to be compliant and how to not be compliant. And I feel like I can switch that on and off based on my need, I guess, or how I’m feeling. But with HIV I feel like I need that medication.”

Noah’s narrative helps us to understand the relationship between the experiences in the two stages, before and after the HIV diagnosis. While the experience in stage one is broader in terms of specificity, it seems that previous experiences with medications might influence current experiences and behaviors.

The health care practitioners taking care of people living with HIV/AIDS need to acknowledge the possible relationship between past and actual experiences. The patient brings past experiences that may influence current ones. The transition phase is crucial as the patient often times already has his knowledge constructed and the patient’s perception can be either reinforced or dismissed regardless of its accuracy.

Thus, to summarize the initial explanation of this model, it is proposed that the patient’s medication experience may begin before the diagnosis and the prescription of

drug therapy. While the experience in the pre-diagnosis – Stage One – is more general, the second stage consists of more sensorial experiences in which the experience is built upon the lived experience of taking medications to treat HIV/AIDS. These results are corroborated by previous work that suggested that the patient's medication experience could start even before the patient takes the chronic medication (Shoemaker & Ramalho de Oliveira, 2008).

HIV/AIDS as a manageable disease: "Cheating death"

The success of an effective drug therapy to treat HIV/AIDS was relatively low before more potent drugs were approved in 1996. Protease inhibitors changed the course of the disease (Holtgrave, 2005; Préau, 2004). Nevertheless, despite clear improvements in the effectiveness of HIV drug treatment, to this date, AIDS is still an incurable disease.

Before the discovery of protease inhibitors and later other classes of anti HIV drugs, the result of an HIV test might have been sufficient to infer the meaning of a death sentence to the patient. This was the case for Beni and Johnny. At the time of their diagnosis, both participants were asymptomatic. They claim that they never had any symptoms resembling HIV or AIDS. In this study, they are the only participants who received a positive HIV test before the availability of a larger arsenal of drugs to control HIV infection.

Beni did not receive medical care. Neither did Johnny, who did not tell his general practitioner about his HIV condition for the next five months. He states:

“I didn't actually tell my doctor until probably about, it was December, actually right before Christmas and it's probably about May before I told him, because I spoke to a friend of mine in San Francisco and what he told me, and actually that comes with the Red Door, he said the same thing is, if your insurance company finds out, they'll most likely drop you. So, you shouldn't get care until you need it. When I finally realized now this is such a catch 22. I, if I don't get care, I'm gonna get sick and then they'll find out and then they'll drop me. So, but, of course, they didn't drop me.”

The meaning of a death sentence attached to the HIV positive test was related to the lack of effective treatment as well as lack of patient-practitioner alliance. Johnny did not trust his doctor. He was afraid to be expelled from the health insurance plan. On the other hand, Beni did not trust medications. His perception was that people with HIV were dying because of AZT rather than despite of using AZT.

Participants who have experienced HIV-related symptoms tend to perceive the seriousness of the disease with more prominence than those who were asymptomatic when they discovered being HIV infected. Also, those who experienced HIV symptoms are more willing to credit their medications as the key factor for bringing them back to “an almost normal life.”

The other participants did not perceive HIV infection as a death sentence. Donovan, Felix, and Billy were symptomatic when HIV was found in their bodies. Despite being severely ill, these participants were more positive towards the management of HIV. Their narratives suggest some relationship between the improvement in their health condition after being seriously ill in the hospital and the use of medications. Thus, they credit their medications with positive outcomes.

Donovan was in the hospital when his doctor suggested an HIV test. He was admitted after a sudden grand mal seizure. His doctor suspected an underlying condition for the unexpected seizure. Donovan says, “that’s when I found out that I was considered not HIV but it was full blown AIDS.” Donovan viral load count had stellar numbers, “it’s like over 500,000 or 400,000” while “CD4 count was two or three.” Despite the terrible scenario, Donovan still kept his faith as he emphasizes: “I honestly, even at that point it’s like I didn’t see it as a death sentence.” His doctor approached him in a serious tone. Donovan’s condition was serious. According to him, he was diagnosed with “full blown AIDS.” Nevertheless, despite the seriousness of his problem, he was given hope. The hope, for him, was in the form of medicines.

The death sentence aspect attached to a HIV positive test resulted in a meaningful theme that is pertinent to all participants, in one way or another. Johnny and Beni explicitly state that the HIV positive test result meant a death sentence. Conversely, Donovan negates the death sentence meaning of his recent diagnoses. The differences on their approaches may be a result of different factors. First, the availability of drug therapy at the time of their diagnosis may explain the behavior of their health care providers. For Johnny and Beni, their providers did not offer a positive prognosis as the only drug available at the time was AZT. Conversely, Donovan’s physician approached him with a more positive view of the problem. According to Donovan, his doctor told him “there are new medications that are coming down the pipeline.” It seems that Beni and Johnny were not at the center of their doctors’ practice. The practitioners did not focus on the patient, but on the disease. They did not approach the patients with an open perspective. It is also

clear that there was a lack of trust between practitioners and patients. Therefore, no therapeutic alliance could be built at that time. Whereas Donovan seemed to be more at the center of his doctor's investigation, it may also be linked to the setting in which the diagnosis was given. Donovan was in the hospital. The availability of effective drug therapy is also an important dimension to be considered. Donovan discovered being infected by HIV when the combination of antiretroviral drugs was being tested. The year was 2003. In fact, Donovan joined a clinical trial aimed to test the effectiveness of a new combination of antiretroviral drugs.

The discovery of antiretroviral drugs did change the course of the HIV infection. In the scientific community AIDS was not seen as a deadly disease as it used to be in the first decade of its known existence. In the first years of the twenty-first century, study results were showing that AIDS could be managed. A person living with HIV could survive for several years. Thus, while Beni and Johnny had no hope but AZT, Donovan had both a larger drug arsenal as well as hope delivered by his doctor.

Billy shares the perception of AIDS not representing a death sentence. He credits medications for this. Billy shows confidence in HIV treatment and motivation to continue his treatment. He says "I just look at people when the first disease started...then Magic Johnson. And I think in some ways it kind of motivated me."

Felix did see the improvement in his health condition as a result of drug therapy. His health condition was severely impaired by a series of health related problems for no apparent reason. He started drug therapy after a series of health problems. He narrates his encounter with the HIV diagnosis:

“My eye surgery started at the end of '07. Then in '08 I was hit by a drunk driver and was in the hospital then with, you know, taken away in an ambulance. I ripped my forehead back, I had cosmetic surgery for that and that was the beginning of the antibiotics. And then I had more eye surgery. And then I had fallen, I stepped back and fallen -- I was sitting down on the edge of a curb, the curbs that are just car width so they have a sharp edge. And I went to the emergency room to one of the local hospitals to have it treated and bandaged. And had a healthcare nurse come to my home to change the bandages because I couldn't reach them. And I think she came, I think every other day, and about the third time she said “I'm going to call a doctor because you have a temperature of 104 and tremors.” So, I drove myself to the hospital, checked in, and they started me on intravenous antibiotics for five days. No one told me what the problem was but I overheard the doctors whispering, and I heard the term MRSA. You know MRSA? It's a severe form of staph infection. And then when I was discharged they had installed a PICC line. I had a home care nurse come to my home every other day for three weeks with more medications and more skin cancer surgery. Then I've been having a problem that my primary physician couldn't identify. He said I just can't find anything wrong with you. This is now in '09. And I said “Well, there is something wrong. We need to keep looking.” He forwarded my X-rays to another doctor that he knew who was a lung specialist who found a spot on my lung, which I then had taken care of with a bronchoscopy and more antibiotics. And about, I'm thinking if I have the times right, about a week after that I had apparently been going through some period of depression, and not eating, and all of this would have, you know, all of this happening in a short time when I had never really been sick in my life. And I had a friend take me to the hospital where they diagnosed pneumonia. And as part of the lab work that they were doing, I was busy reading something else and one of the doctors came in and went through a list of all of the tests that they would be running, got to the bottom and he said “You didn't check this HIV check. Would you like us to check for that too?” I said “Sure, why not?” So, they did and came back with that diagnosis. That was while I was still in Florida. When I came back to Minnesota, which I think was in September of '09, and went in to Fairview Riverside after two liters of fluids because I was so dehydrated and my weight had dropped to 135 pounds. So they putted me on medication while I was in the hospital”

This period marked the beginning of Felix's relationship with his HIV drug therapy. His conclusion about drug therapy is that “it works very well.” He experienced a

near death situation. The medication is seen to control the disease. It does not represent a cure, but a means to survive. Over time Felix was able to see the improvement in his health condition. “When I moved in to assisted living, I did the tour in a wheel chair because I couldn’t walk enough to cover the distance in the hall ways. After a couple of months, I was just using a cane.” Felix acknowledges that medications are responsible for the improvement in his health. He begs for his medications saying, “as long as I have my meds renewed I’m ok.” Also, the perception of HIV/AIDS as a manageable disease is emphasized by his words “it’s amazing to me because everything that I had read about the pill cocktails that people with HIV were taking just to survive. Those days are gone!”

The success of drug therapy seems to be the reason for changing the perception of HIV from a death sentence to a manageable disease. The participants’ narratives confirm this. It is an important element of HIV care. From a patient-centered standpoint, it is even more crucial as the perception of the patient may impact the success of drug therapy. The participants in this study do understand the importance of HIV drug therapy. They see the disease as a manageable condition. For those who received a diagnosis before the availability of effective drug therapy, the perception comes with the idea of “cheating death”. Donovan’s words clearly make the point: “it’s almost like I cheat death over and over again.” Those infected after effective drug therapy became available see the improvement through blood tests.

When positive means negative: "A death sentence"

The diagnosis of HIV infection marks the beginning of the transition to the second stage of the medication experience. The model intends to portray a dynamic process through the stages of experience. It is definitely not a linear process. In fact, the results of this study suggest that experiences are different among the participants. The diagnosis indeed represents a change in the stages of experience. Whereas before the diagnosis the experience was constructed on more subjective perceptions, after the diagnosis, the experience is built upon more objective experiences. The visual and tactile senses add to the sensorial experience as the patient interacts with the anti-HIV drug and start giving meaning to it. In addition, the body starts to react to the distressing experiences of receiving a positive result for an HIV test as well as dealing with the side effects of drug therapy.

The transition between stages of experience is represented by both the diagnosis and the prescription of an anti-HIV drug regimen. All the participants in this study had either indication to begin the HIV drug therapy right after receiving the diagnosis or to consider the possibility of beginning drug therapy. The participants who had the choice of choosing whether to start it right away or to postpone it for awhile did choose the former option. Jack had the option to postpone the beginning of his HIV treatment as he recollects a conversation with his doctor “I could not take medication and just let my body go naturally, go back up and wait until a certain amount of time passes and I may need my T-cell counts might go down again or my viral load will go up to a certain point.” The doctor explained to Jack that he was in the acute phase of the HIV infection. Thus, his immune system would naturally combat the virus and it was a matter of time

for his T cells to reach higher levels. Meanwhile, viral load would decrease. Despite the doctor's information and being afraid of possible side effects of anti-HIV medications, Jack decided to start HIV drug therapy right away. His decision was made based on his experience of "knowing his body" as he says:

"I feel that knowing my body and knowing how my past has had these other issues, with auto immune type diseases [hypothyroidism]. I didn't trust my own body given my history. That's one more reason why I have to take the pill right away."

Because Jack considers his body so fragile, he credits the medication "for bringing that down [HIV viral load]. He continues:

"Because I don't think my own body would've boost my CD4 count or decrease my viral load as quickly. I don't know it would have, like it would made for some other people because I still feel like I'm sort of an odd human being in terms of my autoimmune problem. It's odd that I have this now because I've already had this history of having these really strange, auto immune... I mean hypothyroidism is very common but in men and teenager is not that common."

Jack's narrative emphasizes stage one of the experience proposed in the model. The bottom line is that current medication experiences and decisions are influenced by previous experiences with illness and medication use. As emphasized before, the experience and its stages proposed in the model can be built either on observational knowledge of HIV/AIDS or other disease that the patient may have experienced in his or her life.

The second stage of the experience begins with the diagnosis. The HIV infection diagnosis is often followed by the prescription of a drug therapy prescription. The two variables represent the line between the stages of the experience.

A diagnosis of a severe condition is a powerful factor affecting a patient's life. It invokes change in the way the patient may deal with daily activities. For complicated illness the change is dramatic. Denzin (1998) defines the subsequent changes that the patient may undergo through the course of a chronic illness as "interactional moments and experiences which leaves marks on people's lives... They are often moments of crisis. They alter the fundamental meaning structures in a person's life."

The participants in this study sustain the "moment of crisis" asserted by Denzin. Johnny, for instance, received the positive result on a HIV antibody test as a "very unwelcome Christmas gift. I was actually shocked." It could not be different as he was told that he "might even have two more Christmases to celebrate". The year was 1995 and he got the positive HIV test result on his way to spend the Holidays with his family. The negative prognosis was given to him before any information about treatment availability. Besides the possibility of being dead within a year, Johnny did not know what his options to prolong his life would be.

The meaning of a "death sentence" attached to the positive result of an HIV antibody test is a key factor affecting the initial response to the patient's new health condition. A death sentence was the implicit message delivered to the participants in this study who were discovered being HIV positive before the availability of effective drug therapy to combat HIV infection. Johnny's HIV experience initiated with a negative prognosis. The death was certain in a short period of time as his words suggest.

Usually, the diagnosis of a disease is followed by the patient's expectation of potential interventions. For many diseases, and particularly the chronic ones, the

prescription of drug therapy is the most common intervention utilized by physicians. Nevertheless, therapeutic tools to combat HIV infection in the first half of the 1990s were limited. At that time, the only drug available in the market was zidovudine. The lack of effective drugs to treat individuals infected by HIV put health care professionals in a place where the possibility of death in the short term was a perceived reality. The perceived reality, though, seems to be constructed in the observed experiences in a recent past. The present and future experiences were delimited by the belief that there was not much that could be done to offer a more positive prognosis to the patient.

Another example of that occurred with Beni. He got a positive HIV test in March of the year 1991. He also perceived the positive test as a death sentence. According to Beni, his doctor said that he would be dead soon. He declares, “at that time they told me I had less than six months to a year.” Beni challenged his doctor’s assertion about death. He explains, “[the doctor] was very inept. He was more in fear of the disease than I.”

Medications are the most frequently used therapeutic tool to treat diseases. In HIV/AIDS care, drug therapy is considered by most experts as responsible for placing HIV/AIDS in the list of controllable chronic diseases. In order to be effective, the right HIV drug regimen prescribed needs to be taken systematically. Thus, high levels of adherence are required. For that reason, the experiences lived by Beni and Johnny at the moment they received their HIV test result could not have been worse in terms of an encouragement to adherence to drug therapy. Despite being the only drug available and the effectiveness still controversial, zidovudine was the most effective drug available to combat HIV. Thus, if indicated, it should be taken as prescribed. For different reasons,

Beni and Jonny did start the treatment. Although indicated, but clearly not motivated, both participants started and then postponed the treatment. Beni says “everyone that I knew that took the medication [zidovudine] died.” Despite the factors threatening any willingness to become adherent to the treatment and consequently prolonging their life span, both participants succeeded in their efforts to contradict pessimistic prognostics. After 16 and 20 years, Johnny and Beni respectively, did cheat death and are currently on HIV drug therapy.

HIV Drug therapy and life disruption: "That changes your life completely"

The HIV drug therapy influences the life of the patient living with HIV/AIDS. Johnny says, “that [HIV diagnosis and drug therapy] changes your life completely.” As a result, the patient needs to adjust life according to the new condition. The HIV drug therapy becomes the central piece of the patient’s life. Overall, the challenges presented to the patient on HIV drug therapy are perceived as barriers to having a normal life. The diagnosis of HIV infection and anti-HIV treatment are intrinsically connected as the forces disrupting one’s life. Asymptomatic participants more frequently perceive it. For the asymptomatic patient, drug therapy is what makes him aware of his HIV condition. The proposed model in this study defines life disruption in three different aspects: 1) social life disruption; 2) psychological disruption; and 3) bodily effects.

But what is the change? What is the meaning of living with a life threatening diagnosis? What is it like to live with a death sentence? For Johnny and the other

participants in this study this was a life-changing experience that required major adjustments. More difficult for people like Johnny, who was asymptomatic when he found out about his HIV condition, is the acceptance of a silent virus that has the potential to kill one in a short period of time. He claims that his “whole life then revolved around that [the HIV infection].” He then started questioning — “am I going to live and who can I trust?” This response was not associated with the treatment or the symptoms of the disease itself. In fact, for asymptomatic patients, when there are no signs of the disease, there is still the knowledge and the inner feelings of having the virus.

This study finds that there is a major life change provoked by the diagnosis and it continues with the beginning of drug therapy. All the participants have initiated HIV drug therapy soon after receiving the positive result for HIV infection. The participants had an indication for drug therapy and they describe the moment of starting to take the medication as unique and powerful. According to Jack, who started the treatment less than a month after receiving the positive HIV test, the moment when he took his first pill was a “very, very intense feeling.”

It appears that the feelings and emotions are interconnected with both the drug therapy and the diagnosis itself. When asked about whether their feelings were due to medications or the disease itself, the participants were not clear about their differences. Nevertheless, there seems to be a difference of feelings when the HIV treatment was initiated in a hospital or at home. Those participants who began the treatment in a hospital seem to be less reflective about the meaning of drug therapy and less capable of articulating their reactions to the initiation of drug therapy.

The life changing aspect of starting HIV drug therapy is not necessarily related to the side effects that result from drug taking. Yet, one cannot disregard the impact that side effects may have in one's life. For some individuals in this study, the psychological effects that medications have on one's life surpass the physical impact of taking medications. On the other hand, the results of this study suggest that side effects are a very important life-changing event for someone starting HIV treatment. The mindset of an individual with HIV/AIDS might be educated to understand the biomedical impact of drugs in their lives. Johnny is confident that HIV drugs represent a life change in terms of challenges an individual with HIV has to face. He states:

“Your entire life has been planned around these pills now and if you miss one, even in one time, you could start getting your resistance. And then there are only so many treatments and if you burn through them, they can't help you.”

This narrative shows his fear that resistance is part of the 'deal' and he has to control it. His life now depends on the success of drug therapy.

Among the participants who initiated drug therapy at home, all of them claim to lack AIDS disease symptoms. They represent the majority of participants — 6 in total. According to them, they do not have any symptoms that resemble AIDS. They state that their bodies do not show any signs related to AIDS. They argue that all signs of the disease are represented by the medications. Johnny contemplates that “everything is due to side effects of medication. The HIV itself is not causing any kind of illness or sickness.” Along the same lines, the uncertainty of not knowing enough about HIV and its drug therapy makes participants wonder about the success of their treatment. Felix is

one of those who wonder about his treatment. He started the treatment when he was hospitalized. After being discharged, he claims that he was so weak that he could not ask questions and once at home, “I didn’t know whether anything that I was experiencing was a reaction to the meds or reaction to the disease.”

For others, HIV medication is what makes one sick. Sergio says that he had been asymptomatic before he started anti HIV treatment. Soon after starting HIV drug therapy he experienced a drug failure due to its toxicity. Sergio complains that medications caused more inconvenience than the virus itself. He protests: “they made me really sick.”

Billy claims that his first treatment became a burden to his life. He says:

“I had bad experiences with it. There was side effects and stuff like having nightmares, and delusional, and kind of like night sweats, and everything else in between.”

Another dimension that complicates the life of an individual with HIV/AIDS is the need to add drug therapy to treat other conditions besides HIV. Being on so many medications makes daily life even more complicated, as the patient cannot differentiate whether he/she is experiencing a reaction to the HIV itself or to the medications. If it is due to the medications, one may not know which one is causing the problem. This is the case for Beni who takes three tablets for HIV plus eight tablets for heart problems and other conditions. He complains:

“I’m on so many medications right now [that I don’t know] how much is the heart medicine and how much is the HIV medicine.”

Social life disruption: "My whole life is structured around my medicines"

The results of this study suggest that the life of an individual living with HIV/AIDS becomes medication-centered due to the demands of the drug regimen. The patient has to rearrange his or her life as a result of drug therapy. Besides every day side effects caused by antiretroviral drugs, the participants struggle to reorganize their lives as the demands of medications go beyond side effects. Such demands are represented by the feeling of being tied to a drug schedule and limitations on social interactions with friends and family. Also, it includes alteration of time to sleep, eat, and travel. Noah utters, “my whole life is structured round my medicines.” Noah claims that his life is regulated by the medications he takes every day. He proclaims that he does not experience any serious side effects nor does he have any trouble taking the pill, which consists of a single tablet every night. In fact, Noah expresses his dissatisfaction with his drug regimen claiming “I feel like I am bound to its schedule.” He complains of the impact medications have on his social life and sense of freedom. Because he feels “bound to [his medications] schedule”, he continues, “ I can’t move, can’t go on vacation. I can’t do specific things at specific times.” His life is organized around the medication rather than the other way around. He feels life is structured around his treatment, even though he acknowledges that the drug regimen he is on is considered the most simple in terms of drug schedule on HIV drug therapy.

Despite the distress caused by drug therapy, Noah is aware of the necessity of being compliant to HIV drug regimen. He claims to be compliant to the drug prescribed to him. He says:

“I think in four years roughly, I may have missed just a handful. I never know when I miss them because I don't think I do miss them. I know that I have missed a few times, I know I have. But over the course of four years, I would say that I haven't missed more than 10 tablets so I think I'm compliant. I'm pretty compliant with it.”

Over the course of this study, between the first and second interview, Noah did either miss some doses of his medication or altered the way it is expected to be taken. His notes are as follow:

“I fell asleep again without taking my medication. I woke up at 10am and found my tablet resting on my nightstand. I took it immediately” (Noah notes on November 6, 2011).

The drug Noah takes is indicated to be taken at bedtime on an empty stomach as a way to prevent side effects such as “dizziness, headache, trouble sleeping, drowsiness, trouble concentrating, and/or unusual dreams” (Atripla). Noah is aware of it as his journal notes suggests:

“I got out of bed and decided not to have my morning breakfast as they may keep the medication from absorbing quickly and correctly. I was nervous that I may experience some side effects such as short attention, mild confusion, and a light alteration of consciousness” (Noah notes on November 6, 2011).

The drug-centered life represents the situation in which the patient has to organize his or her life around the drug regimen. It is important that health care providers are aware of the life style of the patient, whether the patient is able to take the drugs as prescribed or not. Johnny did experience the life around medications with a previous drug regimen. He recollects it:

“I tried a few things [drug regimen] right at the beginning. It seemed to me it was, might have been, maybe the first one. I took two different drugs and so it ended up being eight times a day dosing because one drug was five times a day and one drug was three times a day. And so, you have to get up in the middle of the night, take a pill and fall sleep again. At work, it was terrible because I was doing video production at that time and we have a film crew. There is no way I could just slink off to take my drugs. So, you know, I've bought an expensive watch because it had a beeper on it. So I'll go, just a minute. But still, I didn't want to take it during my break and then it always ended up screwing up my cycle of timing because that probably, like an hour or later or sometimes you'd forget, so it will be two hours. And so it was very frustrating, it was frightening because like every time that it goes late, I thought, ‘Okay, is this gonna start causing problems.’”

Johnny did not receive much support to help him with his treatment. He claims, “there was no counseling of any kind. Anyone to talk about it. In fact, I didn't know how many times it's dosing. It wasn't until I got to the pharmacist and got the pills and he said five times a day.” The drug-centered life did influence Johnny’s medication taking behavior. He says, “it was almost impossible [to be compliant].”

It is important that health care providers acknowledge the patient’s life style. The HIV drug therapy, like any other drug regimen, is only effective if it can be taken as prescribed. It is crucial that the patient becomes aware of the consequences of changes in drug therapy.

The proposed model does not necessarily represents a linear process. In fact, the patient’s relationship with HIV drug therapy is a very dynamic process. The association of variables may sometimes present some overlapping. For instance, when social life is

disrupted by side effects of anti-retroviral drugs. Johnny explains how side effects of anti-HIV medications may affect his social life. One the most common side effects of HIV drug regimen is diarrhea. Thus, Johnny explains how it impacts his social life. He says:

“You don't eat when you're walking around a lake. Sometimes you don't eat anything. You just really had to be cognizant about the fact that you might have this issue [diarrhea] so that I skip a camping trip with a bunch of my friends cause I thought ‘I'm not going to be running out in to the bushes or to the camp bathroom constantly.’ I didn't want to tell them what my diagnosis is and I just thought that this would be uncomfortable at best. So I made up a story and skipped it. Even things like walking around the lake like I said or sitting through a movie, sometimes it'd be scary. I think, ‘oh my God, what if it hits right now?’ Man, it's so painful to hold that.”

Johnny highlights the complexity of the life disruption resulting from of HIV drug therapy. His social life is disrupted by the use of anti-retroviral drugs. The disruption is caused by the side effects that prevent him from doing daily activities. Thus, the result is a natural isolation of the patient from his group of friends. Such isolation may be due to the stigma associated with HIV infection, which, in this model, is represented as a psychological life disruption that is discussed in the next section.

The drug-centered life is reinforced by lack of knowledge about drug therapy. The patient often times does not know if the medication needs to be taken at the same time every day. Noah's journal excerpts deal with this issue. He writes:

“My mom is visiting me tomorrow afternoon, so I want to go to bed early and go to work at 7 instead of 8 so we will have more time together tomorrow. But when will I take my medication? I haven’t decided yet. Should I take it now (9pm), which is 3-5 hours earlier than my normal time. Or should I wake up by alarm at 1am and take it? I feel conflicted. I’m realizing as I write this that my medication has a strong grip on my life and my decisions. I don’t like how much thought and work I have to put into planning my bedtime and subsequent administration of medication. Although I feel like the meds are just a part of my life, writing about it makes me realize that it is a huge part of my life. It regulates my decision-making, my bedtime, my day. Furthermore, all the work I have to put into my healthcare is at times overwhelming” (Noah journal entry November 7, 2011).

The variation of dose timing in Noah’s drug therapy is a cause for constant preoccupation and distress. It is uncertain how the variation of dose timing in HIV drug therapy is a key factor for virologic resistance. The studies on drug adherence tend to focus on adherence in terms of percentage of drug taken according to what is prescribed. Dose timing and virologic resistance are not yet fully uncovered (Liu et al., 2006).

Psychological disruption: “HIV is not like cancer”

The second aspect of life disruption in the proposed model is represented by psychological disruption. This element deals with the patient’s subjective perception of HIV medications’ use. The psychological disruption is associated with the perceived stigma of HIV infection. “[HIV] is not like cancer”, says Beni. The psychological disruption may influence the patient’s relationship with medications in ways that the

patient tends to hide medications from family members and friends. In addition, the participants avoid taking medication in public. Noah comments in his journal about this issue:

“I store my medications in the closet to keep them safe and out of view from other people who may be in my space. I think that if someone, a roommate or a guest see the bottle, they may ask questions about my medication.”

Just hiding the bottle is not sufficient to Noah prevent someone to find out about his illness. He mentions it in another journal entry, on November 27th. He writes:

“I have some psychological mental aversion to throw them out [empty medication bottles]. One thing I know I have done when I throw them out is I scrap my name off the bottle in fear that the bottle could be retrieved from the garbage or discovered by someone.”

The fear of disclosing one’s HIV status is observed in the literature on HIV/AIDS and stigma. In fact, studies suggest that people living with HIV/AIDS may postpone treatment or skip doses due to fear of other people finding about their HIV status (Haltkitis & Kirton, 1999; Johnston Roberts & Mann, 2000).

In this study, the participants do not postpone treatment nor regularly skip doses as a result of hiding medications. Eventually doses may be missed. Nevertheless, it was not found as a regular practice among the participants. The fear of someone finding about the HIV status is a psychological burden that has other implications to the patient’s life. It disrupts life in a way that the patient tends to isolate himself or herself from others, thus, preventing access to trustworthy information about the illness and its treatment. The

avoidance of the topic of HIV infection is a constant preoccupation to Noah. He claims that people avoid talking about HIV due to fear of it. He says:

“I think a lot of people are afraid of HIV. So I don't feel at home necessarily in this society, which is sad in a way but-- I don't appreciate living somewhere where I'd have to kind of be the pariah, I have to kind of guard myself against stereotypes or rejection.”

In this study, whereas the disruption may not directly influence drug taking behavior, it is a cause of constant suffering. Cassel (1999) has an interesting argument on the moral dimension of suffering. He defines suffering as “the affliction of the person, not the body.” The psychological disruption has an impact on the lived world of the patient. There is a feeling of being guilty and discussion about HIV is avoided as much as possible. Beni illustrates this point:

“If you're calling to work and say 'I've got [a sexually transmitted disease] and I can't make it in today because I have to go for treatment', everybody would go, whoa! Right? It's different from saying I've got pink eye at the beach. That doesn't mean that you're extremely sexually promiscuous, things happen. But it's amazing how we have all these garbage and a I think a great deal of it is because it is dealing with a disease that is pretty much sexually transmitted because not many people are getting it from transfusions.”

Beni complains about his sexuality being the focus of others' perceptions about his behavior. It is like being a homosexual will make the person promiscuous and, consequently, being blamed for the HIV infection. This is not the way the participants in

this study want to be seen. Sergio points it out saying “my sexuality doesn’t define who I am.”

To the participants in this study, being on HIV medications is also a cause for shame. The underlying reason of the perceived shame may be the illness itself. Nevertheless, the HIV medication is the symbol legitimizing the illness. Thus, HIV drug therapy is not like the other treatments used to manage other health problems such as the hypothyroidism experienced by Jack. He says:

“It was not a big deal [taking the pills for hypothyroidism]. There was nothing really...there was no shame of that diagnosis. It happens. It’s like my thyroid just didn’t work. It didn’t produce that hormone. Okay, I want to take the pill. But for HIV, it’s like...it’s really different. And it’s serious. If I don’t take that pill, if I didn’t take that treatment, it could definitely shorten my life and...I guess hypothyroid could eventually do that too but I didn’t think of it that way at all.”

The stigma and uniqueness of HIV infection places the patient in an isolated position. The difficulty sometimes includes access to appropriate care. For instance, filling a prescription for HIV medications was a constant problem to Johnny:

“I came here for care upstairs at the Delaware Street Clinic. Before I used the pharmacy over by my house. I wanted something different anyway because I think I’m the only HIV patient within several blocks. So they never have my meds. So every month I had to struggled with that.”

The participants complain that often times the focus of health care providers is on the disease rather than on the patient and her or his immediate problem. Kelly argues on this issue:

“The doctors outside the HIV clinic think everything is related [to HIV]. When I come into the doctor’s office they always say ‘well, how’s you HIV?’. I have to say, ‘I’m sorry; I’m here because my toe is swollen. What the hell does that have to do with HIV?’ That is annoying. I’ve gotten to the point now to where I don’t tell a doctor who is not my regular doctor that I’m positive unless it comes up in the system. I’m just tired of that reaction.”

Bodily effects: “It’s the way it is”

The literature on HIV treatment adherence provides evidence suggesting side effects as one of the major causes of drug therapy discontinuation (Roberts & Mann, 2000; Golub, Indyk, Wainberg, 2006).

In the proposed model, side effects are often recognized as bodily modifications. The bodily effects category is the third cause of life disruption as it is a major issue in the patient’s life. In this study, all the participants experience some kind of side effects. However, for the majority of them, it does not prevent medication taking. The participants perceive side effects as “part of the deal.” As Sergio states, “it’s the way it is.”

Billy is the only participant claiming side effects as the reason for abandoning the treatment. In fact, he could not handle the demands of his previous HIV drug therapy as he explains:

“The other one I had bad experiences with it. There was side effects such as nightmares, delusions, and night sweats, and everything else in between. I was

just not comfortable with that. So I was somewhat taking my meds on and off because I didn't really like the side effects."

The side effects experienced by Billy are mainly common in the beginning of the HIV treatment. Nightmares and night sweats are commonly associated with the drug efavirenz, which is one of the medications most used in initial therapies. Other participants experienced the same kind of side effects. Felix compares the nightmares as to be on an 'acid trip' as he explains:

"And I had really bizarre dreams. I would have imagined that being on an acid trip would be like. I mean I just was in places that I didn't recognize and would suddenly be transported to another area that I didn't recognize and didn't know how it happened. And I went through that maybe only a couple of weeks."

The nightmares, despite happening during 'only a couple weeks' were embarrassing enough to him. He says:

"I don't know what I was doing there [in the dream] but that was as bizarre. I was staying at my son's house. I think I crawled through the bedroom to the bathroom. But in my mind I was crawling through an Indian village and trying to avoid being captured. So I got into the bathroom and urinated apparently in the waste basket."

Felix still experiences nightmares. Nevertheless, it is not as extreme as it was in the first weeks of treatment as he recollects:

"It took me a while to get through that. I still have very vivid dreams almost every night but not extreme...not too extreme."

Other participants such as Jack also experience the nightmares resulting from antiretroviral taking. He tells:

“There aren’t a lot of side effects. I know there are a lot of worse things that are out there from other drugs. I saw my Mom went through the chemotherapy and radiation. I only had few types of side effects. I have like vivid dreams. I have racing thoughts at night and I can’t stop thinking at night. It drives me nuts...these racing thoughts that I have at night are really a bummer to have because you feel exhausted by the time you wake up in the morning. And I’m slow to get going in the morning. I wouldn’t call it dizziness anymore, although if I get up at 2 a.m. or 3 a.m., then I’ll be dizzy. Once in awhile, I still have some minor hallucinations or I see things, images, mainly bugs.”

Billy, Jack, and Felix did share the same kind of side effects. Billy is the only one who did not accept the treatment. He claims side effects as the reason for abandoning the treatment. Nevertheless, being on denial may also be a reason for quitting the treatment as his words suggest:

“I didn’t actually take medicines right away. It was like I had to let that settle down. I know I just had to grasp the reality of me living with HIV. So I was like in depression mode, denial [about the HIV infection] until I finally accepted it. It took me a while to accept the fact that I’m [HIV] positive.”

Although Billy still experience side effects, he claims to be adherent since he got back to his HIV treatment. It has been over a year as he says:

“It doesn’t really have all the bad side effects like the other one I had before. So it’s more and more easier for me to tolerate. And now it’s just... I just take my pills and I’m fine as long as I’m making sure that my CD4 count is undetectable.”

The side effects of HIV medication represent the bodily effects disruption in the proposed model. Rather than focusing only on physical modifications resulting from HIV treatment, this category deals with perceived severity of side effects and how the patient handles the situation.

Studies show that prescription modification is a strategy that the patient may use in order to cope with side effects. Such strategies include reducing drug dosage and skipping doses, among others (Pond et al., 2005). Furthermore, ‘drug holidays’ is also a strategy used in order to try to minimize side effects of drug therapy (Barton et al., 2000).

In this study, side effects do not prompt adjustments in the drug therapy per se. Nevertheless, the participants do have their own way to minimize the effects of drug therapy. It does not include skipping doses or ‘drug holidays’. Interestingly, there is a tacit acceptance of what may be seen as ‘minor’ side effects such as diarrhea and dizziness. Jack explains his rationale to deal with such side effects:

“Side effects? I’ve tried a lot of different things. I’ve tried to eat a few crackers with the pill at night. You know, it says to take the pill on an empty stomach. Well, I might... maybe I’ll try a few crackers and see what happens. It doesn’t help. I tried to take the pill earlier at night. So I tried to eat my dinner earlier and then I could take my pill earlier, right? Like maybe nine o’clock versus 10 or 11 and I go to bed right away. Well, I still have the same effects at night...the only thing it helps when you take the pill earlier is that it may help a little bit with this flow to get going for you in the morning. I’ve never been a morning person to

begin with, but I could easily get up at 6:30 or six and get going. Wake up and get going. I can't do that now. And if I take the pill a little bit earlier, that part is a little bit better. But either way with the dizziness, the hot head, the very warm head feeling all night long, the dreams, the racing thoughts...that's continuing...not as bad as when I first started."

Jack does not consider skipping doses or discontinuing his treatment, because medications are "the only way to survive." As Shoemaker & Ramalho de Oliveira (2008) suggested, to deal with the side effects of the HIV medications seems to be considered by patients as a trade-off because they cope with these symptoms in order to control a very serious infection and, consequently, survive.

The participants evaluate the antiretroviral medications as necessary. Thus, the only way to achieve the goals of therapy is to take the medications as prescribed. The patient may try to boost his or her immune system with changes on his or her diet. For instance, Felix tries to drink grape juice to increase the effectiveness of his medication. He explains:

"I just read yesterday that grapefruit juice can have an effect on the effectiveness of Atripla®. I buy grapefruit juice in half-gallon containers. I don't drink maybe more than four ounces at a time or during the day. So, I don't drink much of it as most of what I followed up on indicated that if you're not taking massive amounts it's not that much of an issue."

What Felix perceives as positive has a negative association to Donovan. Whereas the former believes that grapefruit juice is helpful for his health, the later associates the juice with an intensification of the side effects. Donovan explains:

“I used to take the medication Sustiva® and Trizivir® in the morning with oranges. And for some reason, it’s like at least to my knowledge, it would make me have, I’ll have diarrhea or loose stools. It’s like anything citrus...orange juice, lemonade, and grapefruit juice. It’s, not a good combination with these drugs. So I avoid those and that’s the only side effect that I have.”

The participants in this study are not in favor of adding other medications to their current HIV drug therapy. With few exceptions, their preferences reside on changing diet or using non-pharmacological products such as Felix’s grapefruit juice. Other participants such as Sergio use organic food to improve his health condition.

The acceptance of side effects as part of the HIV treatment seems to be related to the perception that HIV drug therapy is the patient’s last resort to extend his or her life (Wong and Ussher, 2008).

Felix complains about diarrhea and fatigue. He says that he has “bowel movements at least three times in the morning.” Despite being uncomfortable with that, Felix refuses additional drugs to resolve the issue. He believes that every medication causes side effects. Therefore, the addition of another agent on his daily regimen will cause more side effects that will require additional drugs. He argues “I would rather be managing it some other way or accepting it, dealing with it rather than taking more meds to do it.” He is complacent with side effects and accepts it as “part of the deal.”

Observing improvement in overall health condition also helps the acceptance of side effects. Felix adds:

“As long as I see the lab results, I’m fine with that.”

Meanings of HIV drug therapy

Meaning can be defined as a set of feelings, actions, and thoughts that are linked together to things or behaviors (Moerman, 2002). The construction of meanings about any given treatment is a way for people to make sense of their lives and to associate a required treatment to their health problems (Conrad, 1985. Wong & Usher, 2008).

In the proposed model, the meaning ascribed to HIV medications is another dimension associated with the experience of utilizing HIV drug therapy. It directly influences the patient’s relationship with drug therapy. In the proposed model, two properties of the meaning of antiretroviral drugs are identified. First, the negative meaning related to the medication being seen as an illness reminder. Secondly, the positive meaning of the medication being considered as a life savior.

The properties have influence on the patient’s relationship with drug therapy. While the HIV illness reminder can make the patient contemplate non-adherence to drug therapy, ascribing a positive meaning to drug therapy may positively influence drug taking behavior.

The following section discusses the meaning ascribed to HIV drug therapy by the participants. Meanwhile, it discusses the relationship between the meaning of drug therapy and its influence on drug taking behavior.

Medication as an Illness reminder: “It’s an everyday reminder”

The first meaning of HIV treatment is the illness reminder aspect associated with antiretroviral drugs. The narratives of the participants suggest the negative connotation associated with HIV medicines when they are seen as the reminder of HIV/AIDS.

The participants in this study did not abandon the HIV drug therapy due to the negative meaning associated with the use of antiretroviral drugs. Nevertheless, such negative meaning is often times mentioned as a burden to drug adherence. The participants contemplate non-adherence as a result. Jack suggests it by saying, “it's like if I didn't have a pill I could forget about the whole HIV thing.”

The illness reminder aspect of HIV medicines is a constant aspect of drug therapy. Kelly is assertive about it. She says, “it’s an everyday reminder [of the HIV condition]. Every day.”

The illness reminder meaning has no association with the side effects of HIV medications or the number of pills taken. Indeed, this meaning is ascribed even before starting the treatment. Jack illustrates that by recollecting the first time he took his first anti-HIV pill:

“I remember the first night when I was to take my first pill. It was a big pink pill, pretty large. And suddenly I’ve never been used to take such a big pill, like my dad calls them horse pills. For me was just...was a mental struggle taking that pill for the first time. It was so powerful. I was scared. Really scared for what this could mean to me. I was really scared that it means every day I take that pill from that day forward. It’s a reminder of what I have.”

Despite the negative meaning of HIV drugs, it does not prevent Jack to be adherent to drug therapy. Nevertheless, it is “stressful and uncomfortable.”

In this study, the HIV reminder aspect of medications does not have any association with the number of prescribed pills. Jack, for instance, is on what many health care providers see as the simplest drug regimen — the one pill-per-day treatment Atripla®. However, he still recognizes the psychological burden associated with taking a medication to treat HIV/AIDS.

Kelly is assertive about the lack of association between the number of prescribed pills and the negative meaning of anti-HIV medications. She claims that through her life she has been used to take pills on a regular basis. She clearly emphasizes that the inconvenience of taking pills every day is not linked to the number of pills, but to “the meaning of taking it because I was taking vitamins every day and it did not have the same meaning.” The negative meaning associated with HIV medicines is indisputable as to her vitamins “are good for you to take every day.” Her strategy to dissociate the negative meaning of HIV drug therapy is to pretend that HIV medicines are like the vitamins she used to take everyday. She tells “[HIV medications] are good for me and essential to keep me healthy so I have no choice but to take it.”

On the other hand, a large amount of pills is seen as an inconvenience rather than an aspect associated with the meaning of HIV treatment. Kelly illustrates the point by saying that “there was one regimen which I actually cried when [the doctor] told me what I had to take because it was just too much.”

The reminder condition is primarily associated with the HIV pill itself. Jack says:

“Every time you take those [pills] you can't forget because you have to take these God damn pills every morning. And they just, there you are, you have AIDS.”

Whereas the illness reminder meaning of antiretroviral drugs is mainly a signifier of the drug itself, for asymptomatic participants, the side effects may reinforce the reminder meaning of antiretroviral drugs. Johnny’s narratives sustain that:

“Everything is due to side effects of medication. The HIV itself is not causing any kind of illness or sickness. I have a little bit of a hump in the back and this neck fat was from the medications. It's not in my family and no one else has it. I hate it. That's always a daily reminder for you to see that.”

Other studies also found the illness reminder as a meaning ascribed to HIV medications by patients living with HIV/AIDS (Golub, Indyk, & Wainberg, 2006).

The life savior meaning: “It’s my saving grace”

Whereas HIV medications have the meaning of being an illness reminder, they also have the meaning of being seen as a life savior. The life savior meaning seems to be mainly ascribed by the participants who are either symptomatic or have been hospitalized when HIV infection was diagnosed. The HIV medication is identified as the agent changing the negative prognosis of a “no more than a few months of survival” to a life

with hope of living “almost like a normal life.” This perception is sustained by the improvement of the patient’s clinical condition.

Several participants in this study see HIV drug therapy as a necessary intervention in their lives. For some participants, despite negative meanings associated with HIV drug therapy, they also perceive that as an effective intervention to control HIV infection. Whereas most of the participants would prefer to not use medications, they recognize the importance of the treatment. Felix acknowledges that without medications, things would not be under control. The perception that HIV medications can improve the patient’s life is important to reinforce his confidence on drug therapy. He says:

“I used to think that they [medications] were unnecessary and most problems [health problems] could be treated in some other way, either by changes on diet, or exercise, or something else. I just never took any meds at all until the last couple of years. And my opposition to that has changed. I would rather not need to take them, but I see that taking them does control some issues that couldn’t be controlled at any other way.”

In fact, all the participants corroborate the idea that medications can improve their health condition. There is a dichotomy in the way medications are perceived by the participants on this study. Medicines are seen as a reminder of their HIV condition at the same time that they are seen as the agent responsible for saving their lives.

In one way or another, all the participants identify drug therapy as a life savior. Even the participants who ascribe a negative meaning to drug therapy acknowledge the positive aspect of medications. Johnny, despite the negative prognostic of having “one or

two more Christmases to celebrate”, is still alive after more than 15 years since his diagnosis. He celebrates his contentment saying:

“I’m pleased that medications are controlling the HIV really well. It’s undetectable; it’s just being undetectable for many years now. I’m very pleased with it.”

Noah is pragmatic in his approach to HIV medications. He is asymptomatic and does not ascribe a negative meaning to HIV drug therapy. He says:

“I looked at my medication like this is my life in this bottle. I take this tablet every day to stay alive. It’s not anything, but a tablet to live. So if I don’t take it, there are profound consequences for that to death. So it’s really black and white for me. I don’t look at this as like...Oh, a pill! This is like a little bit of life in a pillbox.”

Noah did not experience any serious health events as a consequence of the HIV infection. Nevertheless, his medication represents his ‘life savior’ and in his view it can prevent serious problems. Conversely, to other participants like Billy, a serious health problem seems to be related to the perception of medications as a life savior. Frequent hospitalizations triggered the life savior meaning of medications to Billy, as he explains:

“It took me getting hospitalized with pneumonia and then with the cryptosporidium to make me see that I just had to own up to it [be adherent to medication taking].”

He complements his assertion about the meaning of HIV drug therapy:

“I think what they represent to me is just I guess... I look at my med box and I just take it day by day. I just wake up thinking I lived to see this day which I’m

thankful for. I think I just look at my meds as a reminder that it's my saving grace. I just look at them as a reminder like I don't want to get sick again like I was before. Last time I was in a hospital I had a viral load of somewhere in the thousands and thousands. And my CD4 was only three or four at that time. So for me to come out from three to four then fast forward to a year now where I'm undetectable that's a lot. That's just beyond belief. So I know that my medications are working and I just feel like that's a reminder of it. If you want your medications to work you have to take them every day. And I think that's what it just represents to me."

Influences on the Patient's Relationship with Medications in HIV Drug Therapy: The theoretical model summarized

The major outcome of this research was to articulate and present a theoretical framework that represents and does justice to the experiences of the participants in this study as they tell their stories about what it is like to live with HIV/AIDS and take medications to control this condition. To summarize, the developed theoretical model represents the patient's relationship with HIV drug therapy and the factors that influence medication-taking behaviors. Its elements are summarized as follow:

Stage one represents all the experiences the patient has before the diagnosis and the prescription of HIV drug therapy. The patient constructs both the medication experience and the illness experience over the period of her or his entire life. In this stage, the experiences are usually constructed through observations of others, especially as the result of the patient's observation of family and friends living with chronic conditions and taking medications. Others' experiences influence the patient's perceptions and beliefs about what is like to live with a chronic illness.

The diagnosis and the prescription of drug therapy mark the beginning of stage two. It should be emphasized once more that even before the diagnosis and the prescription of drug therapy the patient already has experiences that are built on knowledge acquired over time through the observations of others' experiences.

All the participants in this study did have indication to use antiretroviral medications right after the diagnosis for HIV infection. Thus, the model represents the diagnosis and the initiation of drug therapy in the same box. A dotted line separates the diagnosis from the drug therapy because in HIV/AIDS they are intrinsically related.

In stage two, as the patient has the diagnosis and starts taking HIV medications, the patient's medication and illness experience become more sensorial. This means that the patient now is living through the daily demands of HIV/AIDS and HIV medications. At this stage, there are several factors that influence and shape the patient's feelings, perceptions and understandings related to medication taking.

In this study, two main dimensions emerged as the result of having a diagnosis and taking HIV medications.

The first dimension is life disruption. The second dimension is the meaning ascribed to HIV medications. The HIV medications cause life disruption in a patient's life at the same time that the patient gives meaning to the HIV medication.

There are three main aspects of life disruption. The first aspect is the social life disruption. Social life is disrupted by the complexity and demands of HIV drug therapy. The life of the patient living with HIV/AIDS becomes medication-centered. The most basic aspects of the life of the patient need to be planned according to the drug schedule.

The 'drug-centered life' is present even for those participants who are on the one pill per day regimen. As expected, the social life disruption is accentuated in the life of the patient who is on a more complex drug regimen. The social life disruption may also be related to the bureaucracy of getting drug supplies. For instance, the difficulty in having supplies for more than a month. That imposes restrictions on the patient when he or she wants to travel for longer periods of time. The social life disruption may frequently make the patient skip doses of his or her drug regimen. Nevertheless, despite the eventual doses missed, the participant still claim to be adherent to drug therapy.

The second aspect of life disruption is the psychological disruption. This disruption is mainly the result of the stigma associated with HIV/AIDS. The participants infer shame and guilt as reasons for suffering. "The stigma still exists", says Beni. It causes an emotional burden to the patient. The patient tends to hide the drug supplies from others. In this study, the participants do not skip doses as a result of the stigma. Rather, the stigma may prevent the initiation of drug therapy due to denial on accepting the diagnosis. Once the treatment is initiated, the psychological disruption represents a burden that causes suffering to the patient.

The third aspect of life disruption is the bodily effects. This category is characterized by perceived side effects of drug therapy. The bodily effects include diarrhea, dizziness, nightmares, night sweats, fatigue, and all other perceived effects caused by drug therapy. The participants tend to associate body modifications to side effects of antiretroviral drugs. As Johnny says, "everything is due to side effects of medications."

The second dimension of the influences on the patient's relationship with medications is the meaning attributed to anti-HIV medications. In this dimension, the patient ascribes meaning to the HIV medications. The ascribed meaning may influence the medication taking behavior or the patient's intention to become adherent.

There are two categories on this dimension. The first one is when the patient sees the HIV medication as the illness reminder, or HIV reminder. The HIV reminder has a negative connotation. The second category of the meaning of HIV medications is the experience of considering the HIV medication as a life savior. Life savior has a positive meaning.

The HIV reminder is primarily associated with the HIV pill itself. In this study, the number of prescribed pills, or the side effects produced by the HIV medication, is not the main cause for the illness reminder meaning of HIV medication. However, these two variables may reinforce the negative aspect of the meaning. Jack illustrates this aspect by saying "I was really scared that it means every day I take that pill from that day forward. It's a reminder of what I have." The illness reminder meaning makes the patient contemplate non-adherence to drug therapy. In this study, the participants did not engage in non-adherent behaviors as a result of the negative meaning. Nevertheless, the possibility of non-adherent behavior is present in their narratives as "it's like if I didn't have a pill I could forget about the whole HIV thing." The illness reminder is present in the narratives of asymptomatic participants.

The life savior meaning of HIV drug therapy is mostly claimed by symptomatic participants. Those participants who have experienced severe health impairment or

constant hospitalizations are more inclined to give a positive meaning to the HIV medications. Billy says that the meaning of HIV medication for him represents his “saving grace.” The participants acknowledge HIV medications as the main reason for their life extension. The perception of medications as life savior comes through the results of viral load as well as CD4 count exams. “It works”, says Felix. “I can see the results.” The positive meaning associated with HIV medications seems to facilitate drug adherence.

The model represents the results of this study in a visual format. It shows the complexity of HIV medication taking and the factors influencing the patient’s relationship with HIV medications.

It is not the intention of this study to propose a straightforward model that will predict medication adherence. In fact, many previous studies failed in their attempts to predict patients’ adherence to HIV medications. Even though it is well known that the success of HIV therapy is dependent upon high levels of adherence, as this study’s theoretical model suggests, adherence is not a simple goal to achieve. The results of this study show that the patient’s medication taking behavior is complex and dynamic. This behavior is the result of constant negotiation within the patient himself, which depends on his life circumstances and the meanings he gives to them. Thus, the practitioner taking care of the patient needs to become aware of this complexity and try to understand and participate in this negotiation process.

Chapter 5: Closing remarks and recommendations

The results of this research indicate how patients' relationships with their medications are complex in the context of HIV/AIDS. The diagnosis of HIV/AIDS already brings with it a burden to the patient, which is associated with the stigma still present in society. Thus, usually when patients receive their first prescriptions of antiretroviral medications they already have perceptions and expectations associated with them. As previously discussed, this medication experience often exists even before patients start taking the HIV medication. Different types of discourses, such as those from medicine and the social media, are able to influence how one perceives this condition and, consequently its treatment. In addition, patients' experiences are also constructed by observing others such as friends and family members who live with a chronic condition or take medications.

As expected, a diagnosis of HIV/AIDS can function as a disruption in an individual's life both psychologically and physically. These disturbances can shape patients' perceptions, expectations and concerns regarding both the medical condition and the medications used to treat it. For instance, the stigma associated with AIDS can lead the patient to hide from friends, co-workers or family members his or her medications as those are a major evidence that one is infected. On another note, the side effects produced by HIV medications (e.g., diarrhea, nightmares) might lead the patient to contemplate skipping doses or even interrupting the treatment. On the other hand, these medications can be seen as 'life saviors', which would help the patient to

contemplate adhering to the treatment as recommended by the health care provider. Thus, the different meanings patients associate with these medications can influence their drug taking behavior in a significant way, as in the several cases reported by the participants in this study.

When the knowledge of the medication experience is applied to patients' daily lives, it is easy to envisage how significant these experiences are in shaping their decision-making processes regarding medication taking. As these experiences influence patients' decision-making and behaviors, health care providers must acknowledge them. In the context of pharmaceutical care practice and medication management services, this knowledge becomes even more important since the mission of the pharmacist practitioner is to apply her or his knowledge to guarantee the patient is obtaining the best possible results from the use of medications. The results and the knowledge constructed with this study suggest, as corroborated by previous studies (Cipolle et al., 2004; Shoemaker & Ramalho de Oliveira 2008; Shoemaker et al., 2011; Ramalho de Oliveira et al., 2012), that an understanding of the patient's medication experience should become an essential part of the standard of practice in the delivery of comprehensive medication management services. In other words, all practitioners delivering medication management should have the skills to identify, address and utilize these experiences as they work with patients to develop a care plan. As other studies indicated (Shoemaker et al., 2011; Ramalho de Oliveira et al., 2012), the patients' medication experiences can be at the root of drug therapy problems, which means that the effectiveness of the pharmacist practitioner will depend upon his or her ability to identify and work with these experiences in caring for

patients. These same authors present several strategies the pharmacist can use to address these experiences and work collaboratively with the patient to overcome the challenges associated with the chronic use of medications. Some of these strategies are listening to the patient, non-judgmental openness, acknowledge the patient's concerns, and empower the patient (Ramalho de Oliveira et al., 2012). However, more research is needed to understand how effective these strategies are in preventing and resolving drug therapy problems.

The new understandings presented in this research reinforce the idea that the knowledge of the medication experience should be taught in colleges of pharmacy in order to guarantee that the student will incorporate this concept beginning with his or her first contact with pharmaceutical care practice. Understanding the patient's medication experience should be an integral part of the assessment the pharmacist does of the patient's drug therapy. Therefore, besides the collection of objective data associated with medications, the pharmacist must be capable of identifying the subjective experiences of patients with their medications and how these experiences shape their behaviors and expectations.

This study can be considered the beginning of a long journey towards a truly patient-centered pharmaceutical care practice. Pharmacists will only be patient-centered when the patient's subjective understandings of his or her life situations are considered crucial data that will assist the professional decision-making process.

Recommendations for health care practitioners

The medication experience is unique to each patient. As the model proposes, the medication experience can influence medication-taking behavior in ways that deviate from the goals of therapy on HIV care. Thus, it is important for health care providers to assess the patient's medication experience in order to positively influence the medication taking behavior of the patient.

The participants in this study do want to be adherent. They bring to the table their willingness to be adherent to their treatment. Nevertheless, deviations may occur as the lived world is not static. The complexity of HIV drug therapy requires a close relationship between the practitioner and the patient.

The patient is unique and wants to be seen as one. It is important to empower the patient with knowledge about the illness process as well as its associated drug therapy. The participants claim for that, as Donovan's words suggest, "an informed patient is a better patient."

It is important to be open to the patient's beliefs. The patient should be able to feel comfortable with his or her health care provider to express the associated innermost feelings. The medication therapy management provider needs to acknowledge that the patient has the final decision about whether to take the medication or not, even when this decision is unconscious and negative, from the provider's point of view.

It is important to acknowledge the patient as an individual with his or her own beliefs about medications. The patient may understand the importance of the medication but at the same time may not be able to take it as prescribed. The model highlights

thresholds to aspects of meaning influencing the patient's relationship with HIV medications. It should be used as a map to gather the information about the medication experience of the patient.

The pharmacist practitioner needs to have an active role in the patient care process. By active I mean regular appointments with the patient. When the patient initiates the HIV drug therapy, he or she already has experiences that mold his or her own reality. That is equivalent to saying that the knowledge of the patient is real to him, regardless of whether it is based on facts or not. This means that the patient's medication experience will influence the patient's relationship with his medication. The provider, therefore, has to act in the negotiation process that occurs between the drug dispensing and the drug taking. The variables involved in between will define whether or not the prescription will be followed.

It is important to recognize that drug taking behavior is not a static phenomenon as knowledge comes through experience. Knowledge is built everyday. For instance, the patient may understand the pharmacist practitioner instruction in the beginning of the treatment. In the long term, however, he or she may begin questioning the effectiveness of the treatment. Thus, the acceptance of side effects is challenged and the result may affect drug-taking behavior. In the model the acceptance of drug therapy is a result of the perception of the bodily effects disruption caused by HIV drug therapy

Recommendations for pharmacy educators

Bill and Hardgrave (1973, pp. 28) define a model as “a theoretical and simplified representation of the real world. It is an isomorphic construction of reality or anticipated reality.”

The proposed conceptual model resulting from this study intends to show a piece of the world lived by the participants in this study. The proposed model is a tool that can be used in the education of future pharmacists.

The proposed model is simple in its structure, but complex in its explanation. The model is at the same time abstract on the higher levels of the experience and more practical on the lower levels of interaction. For instance, stage one of the experience is abstract in the sense that it does not specify variables affecting the patient’s perceptions or beliefs about the illness and medication experience. Nevertheless, in the lower levels of the model, the model deals with practical events. For instance, when the patient ascribes a negative meaning to drug therapy, he or she contemplates a non-adherent behavior toward his or her treatment.

The model can be used as a pedagogical tool for pharmacy students as it introduces very important aspects of drug therapy as it deals with the patient’s relationship with drug therapy.

It can also be used to highlight the main aspects of the patient’s relationship with medications for HIV/AIDS. It provides an overview of the complexity of the phenomenon. The model intends to provide an overview of the elements associated with drug taking behavior and its complexities.

Although the model is constructed with the experience of people living with HIV/AIDS, it is my understanding that the model can be adapted to other chronic illness contexts. Maybe the most important message of this model is that it does not intend to predict behavior. Rather, it is intended to help educators and practitioners to understand the complexities involved in chronic medications use. The model can be used in any disease context that involves use of medications.

Moreover, educators should consider the use of patients' narratives as a way to contextualize the environment in which the experience of taking medications is constructed. Narratives can be an important strategy to help the patient understand his or her experience as they can help the practitioner in the task of caring for patients. Jack explains how narratives can be helpful to the patient. He says:

“I have like vivid dreams [as side effects of my HIV drug regimen]. I have racing thoughts at night and I can't stop thinking at night. It drives me nuts. And this is something I wasn't able to kind of write down. I've never really been able to kind of describe it to my physician. But now I can. Maybe because I have been more purposely thinking about this. Since I've been in your study it makes me think more about what's going on. So I've been able to describe things more clearly.”

Recommendations for HIV health care programs

The services providing HIV care need to take into consideration the individuality of each patient. The phenomenon of medications use is complex and not straightforward. The interventions should focus on the negotiation with the patient, rather than focusing on adherence to drug therapy.

The participants in this study acknowledge the importance of being adherent to the prescribed drugs. The participants understand the severity of the disease. Thus, they accept their part of ‘the deal’, which is to take the medications as prescribed. There seems to be a tacit agreement between the patient and the health care provider. Nevertheless, such agreement should be made more explicit.

It is important that professionals allow time to listen to the patient’s stories about their medication experiences as well as their illness experiences. Adherence to medication is a dynamic phenomenon that can change over time and usually patients have good reasons to question the need of the medication or to be non-adherent.

Studies on adherence to medications suggest a many reasons for patients being adherent or non-adherent to the prescribed drugs. There is no agreement about that. Meanwhile, predictors on whether or not a given drug regimen will be followed are not consistent (Golub, Indyk, & Wainberg, 2006). This study concurs with previous studies on medication taking behavior that the influences on medication adherence are complex and ambiguous. Thus, a strategy to understand and help the patient with their health care needs is to build a strong therapeutic alliance between patient and provider. The participants in this study call for a strong relationship. Donovan says, “it has got to be a symbiotic relationship.”

The programs caring for people living with HIV/AIDS have to allow time to the patient. Any therapeutic relationship is built on trust. The patient wants to know the provider, as the provider needs to know the patient and his or her beliefs and experiences. This study provides evidence that subjective experiences of patients have a great

influence on their medication taking behavior. Therefore, it is crucial to investigate and deeply understand those experiences when providing care to the patient.

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Appendix A: IRB Approved Consent Form

Consent Form

The medication experience of people living with HIV: from the understanding of the meanings of medications to the development of a conceptual framework of medication experience

You are invited to be in a research study of the medication experience of people living with HIV/AIDS. You were selected as a possible participant because you are at least 18 years old, living with HIV/AIDS and taking medications to treat this condition. We ask that you carefully read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Mateus Alves, a doctoral student, College of Pharmacy, University of Minnesota.

Background Information

The purpose of this study is to understand and describe the medication experience of people living with HIV/AIDS and its influence on medication taking behavior. The study aims to identify key variables that influence or are influenced by the medication experience of people living with HIV/AIDS. The results may contribute to a better understanding of people behavior toward medication-taking and improve patient care.

Procedures:

If you agree to be in this study, we would ask you to do the following things: we would like to interview you about your relationship/experience with your medications to treat HIV/AIDS. We would like to interview you twice. With your permission, the interviews will be tape-recorded. In addition, we would like you to keep a diary in which you are asked to write your reflections regarding your medication experience. Each interview will take about 45-60 minutes while the diary is written according to your available time. Examples of questions include, "What is your experience taking medications to treat HIV/AIDS?" and "How do you manage your medications?"

Risks and Benefits of being in the Study

Participation in this study may include the risk of you feeling embarrassed or emotional when talking about your experiences with your treatments and illness. Nevertheless, you are not required to answer any question that you do not want to answer or write about anything that upsets you.

There is no direct benefit to subjects for participating in this study.

Compensation:

You will receive \$50 gift card compensation for your time and effort for participating in the study. The compensation will be given to you after the second interview is completed.

Confidentiality:

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a subject. Research records will be stored securely and only researchers will have access to the records. After the study is completed, all tape recordings will be erased.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota or with Fairview Pharmacy. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships. However, you will be given the gift when you make a good-faith effort to complete participation.

Contacts and Questions:

The researchers conducting this study are: Mateus R. Alves. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact him or his advisor at the following address:

Mateus R. Alves. Phone: (612) 845-4106. Email: alves005@umn.edu

Linda M. Strand, Ph.D. College of Pharmacy. University of Minnesota. Phone: (612) 991-3324. Email: stran001@umn.edu

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

If you decide to participate, you are free to withdraw at any time without affecting those relationships. ***You will be given a copy of this information to keep for your records.***

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature: _____ Date: _____

Signature of Investigator: _____ Date: _____

Appendix B: IRB Approved Recruitment Flyer

FAIRVIEW UNIVERSITY OF MINNESOTA MEDICAL CENTER

STUDY OF MEDICATION EXPERIENCE OF PEOPLE LIVING WITH HIV/AIDS IN TREATMENT AT FAIRVIEW PHARMACY

THE PURPOSE OF THIS STUDY IS TO UNDERSTAND AND DESCRIBE THE EXPERIENCE OF TAKING MEDICATIONS FROM THE POINT OF VIEW OF PEOPLE LIVING WITH HIV/AIDS WHO ARE CURRENTLY TAKING MEDICATION TO TREAT THIS CONDITION.

If you agree to be in this study, we would ask you to do the following things: we would like to interview you about your relationship/experience with your medications to treat HIV/AIDS. We would like to interview you twice. With your permission, the interviews will be tape-recorded. In addition, we would like you to keep a diary in which you are asked to write your reflections regarding your medication experience. Each interview will take about 45-60 minutes while the diary is written according to your available time. Examples of questions include, "What is your experience taking medications to treat HIV/AIDS?" and "How do you manage your medications?"

IF YOU ARE:

- 18 YEARS AND OLDER
- CURRENTLY TAKING MEDICATIONS TO TREAT HIV/AIDS

YOU WILL BE ELIGIBLE TO PARTICIPATE IN THIS STUDY.

IF YOU ARE INTERESTED IN LEARNING MORE ABOUT THIS STUDY, PLEASE CALL 612-845-4106 MATEUS ALVES FOR MORE INFORMATION.

THIS STUDY DOES NOT INCLUDE PROVISION OF ANY TYPE OF TREATMENT OR ADVICE.

You will receive a \$50 to compensate you for your time and effort.