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Today over 1.1 million people are living with HIV/AIDS in the United States; over the last 4 decades mortality rates have decreased largely made in part because of advancement in awareness and treatment options. Treatment adherence has long been considered a vital component in decreasing HIV/AIDS related mortality and has proven to reduce the risk of transmission. However not all patients take their medicine as prescribed. This research study, sponsored by The North Central Texas HIV Planning Council explored how Patient and Provider communication impacted treatment adherence. By utilizing a mixed-methods approach survey data and semi-structured interviews were used to collect insights from both Patients and Providers. Data gleaned through the interview process provided a perspective that could not be captured by using quantitative methods alone. The results from this research yielded multiple themes related to patient and provider communication with recommendations as to how The North Central Texas HIV Planning Council could address treatment adherence, such as Providers focus on Patients perceived severity based on their understanding of disease and illness; that side-effects remain a concern for patients and should not be dismissed; and finally that the word AIDS is perceived to be more stigmatized and as such organizations providing HIV/AIDS related services should explore alternative names where the word AIDS in not included.
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1.1 HIV/AIDS as a Public Health Crisis

Today 1.1 million people in the United States are living with HIV or AIDS (CDC 2014; Healthy People 2020 2014; Texas DSHS 2014a). The state of Texas ranked third in the United States for highest number of new HIV diagnoses and as of 2013 reported over 76,000 persons living with HIV/AIDS (Texas DSHS 2014b). The Texas Department of State Health Services (Texas DSHS 2014b) reported that in 2013 Tarrant County had 7373 persons living with HIV—the city of Fort Worth accounted for almost 5000 of these cases.

In 2010 the United States took action to formally address the ongoing issue of HIV/AIDS in the nation by initiating a federal strategy to combat this disease. The vision for this strategy is as follows:

The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination. (Obama 2010)

In an effort to address this vision at the state level, the Texas Department of State and Health Services created the Texas HIV Spectrum of HIV Engagement model (Figure 1), [sometimes referred to as the Continuum of Care Model], that would be used to better direct efforts to address issues related to awareness, prevention, diagnosis, linkage to care, medication, and participation in care in order to achieve viral suppression (Lucas 2013; Obama 2010). Efforts to reduce HIV related deaths and
illness in the United States continue to be a priority as is reflected in the Healthy People 2020 goals and objectives (Healthy People 2020 2014).

Figure 1: Texas HIV Spectrum of HIV Engagement

Current HIV treatment protocols have worked to reduce overall HIV-related mortality rates, and as of 2013, 54% of HIV-positive persons in Texas were reported to have a suppressed viral load—indicating that the chances of disease transmission are virtually eliminated (Texas DSHS 2015). It is partly due to the success of treatment options that the number of people living with HIV continues to rise. Now, people living with HIV are able to live a life span equivalent to those without HIV, and HIV has become more of a chronic disease. However, to maintain the suppressed HIV levels necessary for longer life and low disease transmission, medication and clinical adherence to treatment remain a critical component in care. The question posed by this research is: How does patient-provider communication impact treatment adherence?

1.2 Who is the Provider?

When one considers the cascade of care that is involved following an HIV diagnosis multiple providers may be involved, some of which may not have degrees in a
medical related field, yet still provide an invaluable contribution in treatment adherence. In this research, perceptions of “provider” will be challenged by expanding on the roles such as the medical doctor, the nurse, the dentist, and offers that non-traditional providers of health services such as case managers and patient navigators be included in discussions regarding treatment adherence. A brief explanation of their roles is provided to better elaborate on how these positions should be considered as providers.

1.2.1 The Case Manager

Per the Texas DSHS model of HIV Treatment Engagement (Figure 1), following diagnosis the next step is linkage to care, this link is often created through case managers. These healthcare workers assist patients in connecting with a provider who not only has experience with meeting the needs of HIV positive patients, but can provide referrals to substance abuse, mental health services, as well as a number of others that may be needed. This first connection remains a critical component in the treatment cascade and as such case managers, for the purpose of this research, are considered to be providers.

1.2.2 The Patient Navigator

In addition to case managers, patient navigators should also be considered as providers. The Patient Navigator plays a role in filling the gap where the case manager’s duties end and the patient’s responsibilities begin. Patient navigators, true to their title, help patients navigate a new path in the healthcare system. Through training and often first-hand experience, they help guide newly diagnosed HIV positive persons through some of the processes that are involved with treatment and services. They often work to help guide patients towards the services they may need, some of which are not
necessarily medically related, but may link patients to services such as food banks, transportation accommodations, support groups, and community outreach services. Essentially patient navigators offer a psychosocial support element that works as a support function to traditional medical services. This approach to healthcare not only works to establish community building, but also has been shown to improve treatment adherence (Bradford, Coleman, and Cunningham 2007).

1.3 Indicators of Adherence

There is no “gold-standard” for measuring treatment adherence, however current practices regarding treatment adherence are based on self-reporting of the patient and viral load counts. Mugavero et al. (2012) offer that while there is no defining standard for measuring a retention in care, tracking viral load suppression can be used as a good indicator of treatment adherence and patient compliance. Similarly, Palma et al. (2015) and Zinski et al. (2015) suggest a link in clinical visits to treatment adherence (Palma et al. 2015; Zinski et al. 2015). The reciprocal association of office visits and treatment adherence suggests that these two be investigated as one unit.

1.4 Client: The North Central Texas HIV Planning Council

The North Central Texas HIV Planning Council (hereby referred to as the “Planning Council”) is federally funded agency under the Ryan White HIV/AIDS Treatment Extension Act (TEA) of 2009. The mission of the Planning Council is to “provide an effective planning process that involves people living with HIV/AIDS and other concerned citizens, resulting in Quality HIV/AIDS services that are available for, and accessed by, those in need” (“North Central Texas HIV Planning Council” 2015). Centrally located in the Tarrant County Public Health (TCPHD), this agency works with
the TCHPD’s Preventative Medicine Clinic, as well as a number of other agencies found
in and around Tarrant County. In addition to the partnerships created within and beyond
the immediate community, the Planning Council offers a community forum known as
“Positive Voices”. It is during this forum where “clients” of the services can meet and
discuss the topic of the month. These meetings are held at multiple locations and are
also offered for Spanish speaking individuals.

1.5 Study Purpose

In January 2015, discussions regarding potential research topics began. A case
for introducing an anthropological approach was made and well received by the site
supervisor. It was discussed that while previous assessments, often rooted in
quantitative analysis, offered a general idea of what was needed, they may have failed
to capture the voices of those the Planning Council is serving.

1.5.1 Research Questions

The following are the major research questions that guided this research:

- What factors impact the perception of trust in providers—trust in the patient?
- What is the role of communication in establishing this trust?
- Does word choice matter?
- How does the patient-provider relationship influence HIV-treatment
  adherence?
- How does the amount of time a provider spends with patients influence
  treatment adherence?
- What motivates/discourages one to adhere to treatment protocol?
- How do the side-effects of medication affect a patient’s adherence to
  treatment?
1.6 Study Limitations

Due to the sensitive nature of this study, a number of limitations were expected. These limitations are as follows:

- Selection bias: Due to HIPAA restrictions, neither the Planning Council nor their care providers were not able to provide a client list of all HIV positive persons for the interviewer to contact, but were able to help disseminate a survey. This voluntary survey offered an option for an interview, and as a result, many of those who took the survey and opted for an interview tended to have high adherence levels. In addition, those providers who took the survey worked directly with the Planning Council and/or have worked with HIV-positive persons on a daily basis. As the study progressed, it became evident that being able to capture responses from providers not accustomed to treating HIV-positive patients would have provided a further insight not gleaned from those providers who treat HIV-positive patients on a daily basis.

- Survey burnout: While the Planning Council was able to provide a data rich environment, the timing of this study coincided with multiple “Needs Assessment” surveys required for funding purposes, and as such, potential participants may have seen the addition of an optional survey to be exhausting.

- Time commitment: While the survey itself took approximately 15 minutes to take, follow-up interviews asked that participants provide an additional 1-hour commitment. For Providers who already were over-burdened with a full schedule, finding time to participate in an interview created a limitation.
• Lack of randomization: Due to the limited number of responses in the survey and volunteers’ willing to participate in an interview randomization of responses was not achieved.

1.7 Deliverables

A written report was provided detailing an account of how this study was conducted, approached, and analyzed. Also included in the report was a series of recommendations based on the findings of the study. A 45 minute presentation was delivered at a monthly Planning Council Meeting to a group of over 40 persons.
CHAPTER 2
LITERATURE REVIEW

2.1 Setting the Stage

While this study stands on the findings of previous reports, shifts in culture have prompted this topic be re-visited in an attempt to clarify how the patient-provider relationship has changed. To better explore this shift, it is necessary to explore the history and culture of HIV and AIDS in the United States.

2.1.1 HIV/AIDS a Brief History

The history of HIV and AIDS in the United States cannot be fully captured in this paper, however by providing a brief introduction with a focus on topics relevant to this particular study a discussion regarding the impact of HIV and AIDS on the patient-provider relationship is achieved.

HIV is certainly not a new health issue in America, however it continues to pose a threat and as such efforts to reduce HIV rates in the United States continue to be a priority. HIV remains a major health concern (Healthy People 2020 2014). As previously discussed, over 1.1 million people in the United States are living with HIV or AIDS (CDC, 2014;Healthy People 2020 2014). Despite the current awareness, it is important to consider that at one point HIV and AIDS were not diseases that many were aware of.

Prior to the 1980s, AIDS was a disease that was well off the radar in the United States and, in all reality, was not truly discovered until 1984. In 1984, cases of pneumocystis pneumonia and Kaposi’s sarcoma were increasingly reported in gay men living in the Los Angeles and New York regions. Due to the frequency of diagnoses in gay men, the disease was initially branded as Gay Related Immune Deficiency (GRID),
but was shortly renamed Acquired Immunodeficiency Syndrome (AIDS) (Chavan 2011; Kher 1982). A few years later in 1986, the virus linked to AIDS was given the name Human Immunodeficiency Virus (HIV) (Coffin et al. 1986). AIDS and HIV have been historically linked to two groups: gay men and intravenous drug users (CDC 1983; S. Epstein 1996; Courtenay-Quirk et al. 2006). These two “at-risk” populations associate the disease with behaviors considered undesirable at the time, which may have perpetuated the stigma associated with HIV. It could be argued that the categorization of people who were HIV-positive into a certain niches created a stigma that not only reduced the number of individuals who sought testing or treatment for fear of being labeled, but also offered a perception that individuals were not susceptible if they did not partake in such behaviors (Luchetta 1999; Agne, Thompson, and Cusella 2000; Schulte 2002; Welch, Cline, and Johnson 1992).

2.1.2 Treatment

In 1987, the drug AZT (Azidothymidine) became approved by the FDA as a viable treatment for HIV (US Department of Health and Human Services). However, this drug alone did not prove effective and the side-effects were often more deadly than the disease itself. Eventually it was discovered that by combining multiple medications HIV treatment began to improve and show promising results. The term “cocktail” became mainstream, referring to a new form of HIV treatment where a number of drugs were required to help one’s immune system combat this opportunistic infection. As of 2015, there are 39 FDA approved drugs for treating HIV. While some patients may only take
one, it remains common practice for patients to be prescribed two or three different HIV-specific medications (NIH 2015).

Similarly to medications prescribed in the past, adherence to the treatment today remains central to effectively managing HIV. HIV is a virus that learns to adapt much like what is seen in drug-resistant antibiotics, so failure to take the medication as prescribed may result in pathogenic or pharmacological resistance essentially making that drug ineffective. In addition to the risk of resistance, failure to take the medication on time opens the door to a potentially life threatening situation, in that this short window might allow for an infection to take hold of the patient’s compromised immune system. When exploring issues regarding treatment adherence, the complex nature of the HIV treatment protocol itself should be considered. Effective disease management requires the provider to effectively communicate the importance of timing and dose, as well as to prioritize the patient’s understanding of the information being provided. This exchange of information has been linked in part to the patient-provider relationship as it continues to challenge current approaches to treatment adherence (Ickovics and Meade 2002; Sylvain and Delmas 2011; Chesney 2000).

For those not living with HIV, missing a dose of medication does not always pose a problem—they just take it when they remember. For those living with HIV, especially those with a low T-cell count, missing or even delaying a dose provides an opening in which opportunistic infections can take hold (Bangsberg et al. 2001). It is for this reason that is crucial for providers to stress the importance of maintaining a regular medication schedule. This strict schedule demands that a patient be prepared to adjust
their lifestyle to accommodate this challenging treatment regime. For some patients this change in lifestyle creates a barrier.

2.2 Barriers to Adherence

Barriers to adherence come in many forms: the expense of medications, the time lost due to doctor’s appointments, illness, social alienation from family and friends, employability, and side-effects from medication (Obel et al. 2011; Meichenbaum and Turk 1987; Proctor, Tesfa, and Tompkins 1999; T G Heckman et al. 1998; Arnold, Rebchook, and Kegeles 2014). Given the scope of this paper and based on responses offered during the interview process, this section will focus on issues such as the impact of side-effects, stigma, mental and substance abuse issues as they pertain to barriers to treatment adherence.

2.2.1 Side-Effects

The side-effects of HIV medications have historically been associated as being severe and often worse than the disease itself—with issues such as kidney and liver failure, chronic diarrhea, commonly reported. The side-effects with current medications are less severe and for the most part cause little to no impact on a patient’s quality of life. Issues such as sexual dysfunction, lipodystrophy (redistribution of fat), and lipoatrophy (loss of fat) remain and may represent a perceived threat to a patient’s way of life and identity, despite that many of these side-effects have been resolved (Langdridge and Flowers 2013; Flowers 2010; Ammassari et al. 2001). While many of these side-effects have been mediated through the development of new treatment
options, an exploration as to whether or not perceptions of side-effects continue to impact treatment adherence is warranted.

Ammassari et al (2001) argue that providers may dismiss patient concerns regarding side-effects that are perceived as inconsequential to the provider, but may be of great concern to the patient. It is this disconnect that highlights the importance of this study—it is not enough to focus on treating a disease without also treating the patient as a person. Results from this study support Ammassari and colleagues (2001) claim that there is disconnect between patients and providers regarding the perceived impact of side-effects. This gap in understanding is addressed through a qualitative analysis provided in this study which shows that side-effects continue to impact treatment adherence, despite an awareness that the side-effects are less severe.

2.2.2 Stigma

Goffman (2009) notes that stigma tends to be associated in three forms; the first being a body deformity. Second, stigma is associated with individual character, such as mental disorders, addiction, and homosexuality to name a few. This is followed by racial, cultural, and religious stigma. Goffman (1963;2009) suggests that stigma should be seen as a “language of relationships, not attributes” (p.3). For Goffman, stigma is rooted in language and the value that is placed on it. This is effectively saying that stigma is perceived.

Courtenay-Quirk et al (2006) built off of earlier works regarding stigma presented by Epstein (1996) and argued that stigma is an association of blame. Courtenay-Quirk et al (2006) found that a common perception among the gay HIV negative population was that if someone got HIV it was their fault, given the awareness of HIV in the gay
community. With high levels of awareness, at-risk men should know better than participate in risky behaviors and that contracting the virus was a result of irresponsible decision-making. This victim-blaming approach certainly counters efforts to make a patient feel supported and establish trust. During my own study, participants mentioned that Providers were unwilling to treat certain patients because the patient expressed that they would continue to participate in high-risk situations.

2.2.3 Mental Health and Substance Abuse

Living with HIV/AIDS demands that one confronts his or her mortality on a daily basis, which for some can lead to issues such as depression, substance abuse, or a variety of other behaviors that are associated with non-adherence. To this end, it is argued that such behaviors are the risk factors that may be attributed to the initial infection (CDC 2014; CDC 2015; Sumari-de Boer et al. 2012; Wu et al. 2014; Himelhoch et al. 2009). To expand on the roles that risk factors contribute to one’s initial infection would extend beyond the aims of this paper, however interested parties should reference AIDS.gov for further information. Himelhoch et al. (2009) found that while mental health issues are prevalent among those living with HIV, they were less likely to discontinue treatment. Findings of this study found the opposite: substance abuse and mental health issues did play a role in decreased treatment adherence and continue to present as a challenge for providers (see Chapter 4 for further discussion).

Barriers to treatment adherence speak to larger issues often associated with HIV care. Often following a positive diagnosis of HIV, patients are referred to a specialist and in most cases are assigned a case manager to help link them to the care that is needed. In the situations regarding pre-existing mental health and substance abuse
issues, an awareness that these should be addressed simultaneously is recognized, however for patients this is often not the case.

Case managers work to link patients with substance abuse treatments and mental health services as needed, however the ultimate goal of the Case manager is to link patients to HIV care. The dilemma is recognized through an association between substance abuse and mental health issues with non-adherence and the impact of non-adherence with drug resistance (Langebeek et al. 2014; Blair et al. 2011; Royal et al. 2009; Ingersoll and Heckman 2005). Those providing the HIV-specific care might not be fully capable of addressing issues such as substance use and mental health issues and as such patients might be linked to additional services.

2.3 Treatment Teams

Linkage to additional services is not uncommon with immunocompromised patients, such as those living with HIV/AIDS who are vulnerable to a number of opportunistic infections. As HIV treatments improve, those with HIV or AIDS are living longer, and comorbidities related to aging are occurring at a greater pace (Viard 2014; Wit 2015; Falade-Nwulia and Thio 2011; Timothy G. Heckman and Halkitis 2014). Because HIV-positive patients are being treated by multiple healthcare providers, the need to better understand the impact of the patient-provider relationship is necessitated.

As mentioned in the introduction, ‘provider’ is a term that is generally reserved for medical personnel; however, for the purposes of this study, the term ‘provider’ is used in a broader sense in an effort to encompass all members of the treatment team including the MDs, primary care providers, physician assistants, nurse practitioners, dentists, mental health therapists, and case managers involved. To be sure, the treatment team
component of HIV/AIDS care may obscure treatment efforts if providers fail to communicate. It is for this reason that the case manager has proven to be an instrumental player in facilitating and coordinating the care of HIV/AIDS patients. The case manager plays a critical role in coordinating the care for HIV-positive patients and may represent the one member of the treatment team that the patient has the most contact with (Kalichman et al. 2007).

Once diagnosed, the patient is often referred to a provider that is more experienced in caring for the needs of HIV-positive patients. This transition to a new provider offers little opportunity in which a patient and provider can begin to establish trust before initiating treatment. In addition, there might be a delay in care as the patient processes this new diagnosis. The transition between healthcare providers in this situation has given rise to the demand of the case manager position. The case manager, one who serves as a mediator between the patient and perceived services needed, has proven to be an instrumental position in linking a patient to care. It could easily be argued that following diagnosis that the case manager interacts with the patient more than any one provider alone (Kalichman et al. 2007). In an earlier study, Katz et al (2001) explored the impact of case managers in regards to treatment adherence and found that for HIV patients, those who had a case manager tended to adhere to treatment more than those without a one. Katz et al (2001) attribute this in part to a case managers’ ability to address the unmet needs of the patient.

2.4  Patient-Provider Trust

Patient-provider trust is a concept that has been inherently associated with treatment adherence. Hall et al (2001) offered that trust is inherently related to
vulnerability, “trust arises from patients’ need for physicians, the greater the sense of vulnerability, the higher the potential for trust” (Hall et al. 2001, p. 615.). To posit trust as something that is built on vulnerability suggests that trust in the provider is implied and dismisses the many other factors involved. Contrary to Hall et al (2001), a number of studies offered that trust between a patient and provider is built over time rather than implied, and there remains an issue of common ground that must be navigated (Gaston 2013; Langebeek et al. 2014; Safran et al. 1998; Street et al. 2008; Henry 2015; Rajaraman and Palmer 2008; R. M. Epstein et al. 2005).

This common ground is often expressed as a profile based on age, race, and gender. Addressing disparities between these attributes remains a topic of much discussion in the literature (Blackstock et al. 2012; Saha et al. 2010; Street et al. 2008; Schneider et al. 2004; Anastos et al. 2005; Gaston 2013; Duberstein et al. 2007). This paper will explore if the value placed on these attributes truly impacts the patient’s perspective on the trust they place in their providers. It is reported that African-Americans tend to distrust the medical community due to historically verified abuses of power such as those seen in the Tuskegee Syphilis Study (TSS) and Henrietta Lacks (Jacobs et al. 2006; Davis, Green, and Katz 2012). This distrust is not easily dismissed, but rather suggests a provider is of similar race or ethnic background may improve adherence. This paper addresses this question by answering it both from a patient and provider perspective.

2.5 Patient-Provider Communication: Words

Words are an integral part of the communication process and as such addressing the use of words used during the patient encounter becomes fundamental in order to
answer the research questions posed. As recommendations for improved adherence is a major outcome of this study, it only seems logical to begin this section by addressing what adherence means.

2.5.1 Compliance? Adherence? Concordance?

Too often compliance and adherence are used interchangeably, and while by definition they are different, the fact that they are sometimes used synonymously suggests a degree of subjectivity in regards to the value that is placed on them (Miller and Hays 2000; Gould and Mitty 2010; Aronson 2007). The term compliance may illicit feelings of subordination in which the patient may feel he or she has no choice, while the term adherence is specific to patient behavior (Miller and Hays 2000). Concordance on the other hand suggests an agreement in care that the patient and provider decide on (Roberson 1992). Roberson (1992) found that patients and providers have differing views on the meaning of compliance. Per Vermeire et al (2001), concordance suggests the patient as the decision maker and the provider as an empathetic participant in the decision-making process. Langebeek et al (2014) expressed that a shift in perceptions regarding the term compliance gave way to a now more accepted term of adherence. Being able to operationalize what each of these terms mean to both the patient and the provider is central to gaining a better understanding of how to apply their use in in conversations that may impact treatment outcomes of those living with HIV/AIDS. Being able to communicate these negotiable definitions among multiple providers may represent a barrier, as a patient’s HIV treatment team may not always be centrally located.
2.5.2 HIV or AIDS

According to the US Department of Health and Human Services, HIV is a virus which can lead to the disease AIDS (US Department of Health and Human Services 2015). By using this definition, HIV is not a disease, despite that it is often referred to as such. In this study, it was found that many participants perceived HIV to be a disease. Being able to distinguish between perceptions regarding HIV as disease becomes important because beliefs surrounding perceptions about diseases and illnesses are variable and may impact treatment adherence. In an effort to better expand on how distinguishing the difference in these words applies to the current study, an understanding of theories used for this study is needed.

2.6 Theory

For this study a combination of theoretical influences gleaned through both an anthropological and public health lens were used to approach the study and interpret the results. The importance of the patient-provider relationship in regards to treatment adherence is not a new or even novel idea. In 1987 Meichenbaum and Turk wrote *Facilitating Treatment Adherence: A Practitioner's Guidebook*, in which the authors offered that by including the patient in treatment option discussions, considering the patient perspective, leveraging the strengths of non-medical support staff, and incorporating a number of other recommendations to build the patient-provider relationship an increase in adherence could be achieved (Meichenbaum and Turk 1987). Weinstein (1988) built on Meichenbaum and Turk and explored factors such as the costs and benefits, cues to action, and competing life demands. For Weinstein, the Precaution Adoption Model was well-suited for treatment adherence as it ultimately
offered that the main motivation for adherence was self-protection. While these studies are dated, they provide a better understanding as to how responses found throughout the course of this study were associated with the lived experience.

2.6.1 Communication Theories and Models in Health

Byron Good (1994) built off of earlier works presented by Young (1978); (1980) and J. Young and Garro (1982) in which it was argued that social relations may work to produce ideas of ‘illness’. The subjective nature of illness as presented by Good (1994) offers that while the medical discourse surrounding disease is ubiquitous, perceptions of illness remain subjective and transcend social realities because people experience illness in different ways.

While the clinical perception of illness may only extend to the disease, for the patient the illness in itself may extend beyond the confines of the body and become part of their existence. This embodiment, as proposed by Langdridge and Flowers (2013), suggests that while the tendency is to treat the disease, failure to recognize the impact of disease on the person has yet to be fully understood. To be sure, the manner in which patients negotiate, grapple, or come to terms with their disease varies, and as such, it becomes prudent that providers remain aware of how such perceptions become encoded within explanatory models.

Kleinman, Eisenberg, and Good (1978) offer that the use of an explanatory model affords an opportunity in which patients are able to relate their experience in such a way that extends beyond the bounds of traditional biomedical approaches. As previously discussed the interpretation of words used is subjective and is therefore open
to interpretation. For example, is there a difference in the word “illness” versus the word “disease”? While this choice in verbiage seems inconsequential, the suggestion may alter the clinical reality for the patient. Rather than explore what a patient perceives to be their truth, providers may be more inclined to skip rhetoric and instead focus on the topic at hand (Davenport 2000; Henry 2015; M Foucault 1973).

Kuipers (1989) argues that medical discourse needs to extend beyond one in which clinical practitioners impose the language of their profession onto their patients, and instead expand the conversation to include the “reality” of the patient.

Models stemming from a public health perspective, such as the Health Belief Model (HBM) have placed an emphasis on words such as “belief” and “perception” in regards to a patient’s understanding of their susceptibility to HIV/AIDS (Vincke and Bolton 2002; Riley and Baah-Odoom 2010; Lanier and Gates 1996; Schneider et al. 2004; Rosenstock, Strecher, and Becker 1988) but have failed to extend the application of this model to better understand the dynamic nature of communication as a process. The very nature of the HBM is almost lost when one considers how perceptions regarding trust throughout the patient encounter is negotiated.

2.6.2 A Mandate of Trust

A mandate by definition is an act in which someone is given the authority to act in a certain way. There is little debate that when it comes to treatment, the patient is vulnerable to the suggestions of the provider (Baier 1995; M. F. Calnan and Hanron 1971; Hertzberg 1988; Skirbekk et al. 2011). Skirbekk et al (2011) address the role of patient-provider communication in the terms of “mandates of trust”. They suggest that while patients tend to submit to the authority of their providers based on the provider’s
knowledge and expertise, there remained a negotiation in which the patient was satisfied as long as their needs were met. To some patients this “met” need may have simply been a diagnosis, but for others it involved a more intimate “get to know you” visit in which the provider took the time to listen to problems and worked with them towards finding a solution. The mandate of trust is something that a patient gives the provider and is negotiated, though a certain degree of communication strategies that involve not only discussing the illness or treatment at hand, but also the degree to which it affects the life of patient.

Suchman and Matthews (1988) argue that the dualistic nature between disease and illness demands that there is distinction between matters of the body and the mind—thus perceptions regarding having a disease and living with it should be addressed separately. Being ill might imply that a patient feels isolated from others, whereas being sick is temporary phenomena. While synonymous in nature, the value placed on these words is subjective and something that must be considered when exploring the impact of communication approaches between a provider and a patient.

It is commonly agreed that the level of patient trust is positively associated with improved treatment adherence and overall patient satisfaction (Boehmer and Case, 2004; Bonvicini and Perlin, 2003; Fiscella, et al.,2004, Potter, 2002, Suchman and Matthews, 1988, Skirbekk, et al., 2011). However, establishing this trust is not as clear cut as trusting a provider’s expertise, but is fostered through the development of the patient-provider relationship (Skirbekk, et al. 2011). This relationship is influenced by a number of behaviors, mainly on the part of the physician such as body language, eye contact, the asking of questions, tone, showing a general interest in the patient,
listening, and office environment (Boehmer et al. 2004; Dardick and Grady 1980; Fiscella et al., 2004; Lazarus, 1988; Owen, 1980; Potter, 2002; Skirbekk et al., 2011; Suchman and Matthews, 1988; and Wilce, 2009).

2.6.3 Translating Communication to Care

“The spoken language is the most important tool in medicine” (Cassell and Skopek 1977, p. 197). Cassell (1991) argues that in order for a provider to fully communicate with a patient, the provider must recognize the “suffering” of that patient. For Cassell, this awareness begins with the way in which one defines suffering. Suffering, a word that may immediately evoke an association of helplessness for some, might not register as such for others. Current attitudes regarding political correctness offer that it is no longer commonplace to suggest that someone is suffering from an illness, but rather that they are living with it. This shift in discourse, while empowering, might only serve as a veiled attempt to hide the suffering.

For Foucault (1973;1988) suffering is a construct created by society, in that society has limited one’s ability to fully express their feelings without fear of judgment. Cassell (1991) presents an argument stating that since most will never understand the isolation, shift in identity, and judgment imposed on those with a chronic illness, there is a tendency to generalize suffering. But again this begs the question as to whether or not suffering is the correct word to use. For those living with a chronic diseases, such as HIV or AIDS, the ability to live with the disease does not dismiss their suffering. In addition it could be argued that the phrase “living with” suggests a defeatist attitude. How does a provider’s choice of words, “we can beat this”, or “you’ll get through this” resonate with a patient? On one hand “we can beat this” implies a collaborative effort
between the patient and provider, whereas “you’ll get through this” places the responsibility on the patient. This emphasis of word choice speaks to Martin (1992) and Sontag’s (1979) recognition that the body is a symbol that is reflective of societal attitudes regarding illness. Langdridge and Flowers (2013) build off of this idea of embodiment through an explanatory analysis of patients living with HIV/AIDS by showing that a person’s identity may be compromised in such a way that their disease becomes their identity, where they say “I am HIV-Positive” versus “I have HIV.”

During my study I investigated how perceptions of embodiment were perceived. While I did not specifically focus on these perceptions as being a form of embodiment, a distinct association of the body as symbol (Martin 1992) was often referred to as a tool in explaining the importance of adherence.

2.6.4 Exploring Adherence

Singer and Clair (2003) argue that sickness must be conceptualized through a sociocultural lens. To this end, treatment must extend beyond the disease but also focus on the way it impacts the patient’s life as a whole. Treatment adherence is no longer about why a patient is not taking their medication, but rather what factors prevent them from taking their medications as prescribed. Hunt and Arar (2001) offer that while current treatment compliance strategies tend to focus on patient education, efforts should be re-directed to focus on the individual needs of a patient. Treatment adherence cannot be simplified to the point where there is only one solution, but rather should be approached in such a way that works to understand the reasons why some succeed while others struggle. Treatment adherence has long been associated with patient-provider trust, but trust as a tool for treatment adherence has not readily been
explored. Trust is built through patient-provider encounters, and these encounters are built on communication.

Based on literature reviewed, the failure to recognize the role of communication strategies and verbiage used during the clinical encounter limits the progress that can be made toward a provider’s ability to build trust with a patient and ultimately treatment adherence.
CHAPTER 3
METHODS

3.1 HIPAA Compliance

Given the sensitive nature of this study, HIPAA protocols were not only upheld, but measures to protect the privacy of informants remained instrumental to data collection. For those filling out the paper based survey, they were required to sign the informed consent provided; for online survey participants, the survey would not proceed unless the participant acknowledged that they had read the informed consent and agreed to participate in the study. Identifying information was removed from transcriptions and participants were coded using a PT#, PR# assignment, based on whether they identified as a Patient (PT) or Provider (PR).

3.2 Coding

Because this study involves perspectives from both “Patients” and “Providers”, there are situations in which these terms may be used to illustrate respondent’s answers. In an effort to distinguish a respondent from general discussion the words, “Patient” and “Provider” will be capitalized when specifically talking about study participants.

3.3 Recruitment

Participants for this study were required to be at least 18-years old and were HIV-positive or providers of services for HIV-Positive persons. Again, no limitations were placed on defining who/what a provider is and remained open to self-identification. Geographical boundaries were initially considered to include only those counties
serviced by the Planning Council, however was expanded to include areas outside of the service area.

3.4 Contact

Participants were recruited using a multi-faceted approach. Upholding HIPAA guidelines and standards regarding patient confidentiality, patient contact information was withheld from the researcher. The Planning Council staff members utilized a client email list of those who had previously agreed to participate in studies related to HIV care. Planning Council Staff used a scripted email provided by the researcher that introduced the study and provided a link to an online survey. Online participation was also leveraged through the use of social media platforms such as Facebook and Twitter, where a link to the survey was posted on community based pages and various HIV social/support groups. In addition to electronic sources of recruitment, participants were recruited in person at various locations throughout the region such as food banks, group homes, and open community forums such as the Positive Voices group that is led by the Planning Council, where participants were asked to fill out a paper version of the survey.

3.5 Survey Structure

The surveys provided to the participants differed based on whether they identified as a provider or a patient/client. While the general nature of the questions remained the same, some questions were re-phrased to fit the audience. In addition, supplementary questions were specifically targeted to either providers or patients and were not included on surveys where those questions would not apply.

3.5.1 Survey Questions
Survey questions offered multiple choice, ranking, scale, and open-ended responses. General demographic information, such as: age, race, gender, sexual orientation, and income was also collected. Following the completion of the survey, participants were asked to leave contact information if they wished to participate in an interview. In an effort to minimize selection bias, the contact sheet was separated from paper surveys, and for online surveys, contact information was collected prior to importing the data, where after import identifying information was deleted. These measures also protected the participants from any potential breaches in confidentiality.

3.6 Interviews

Prompted by an interview script, interviews were conducted in a semi-structured manner that afforded both the researcher and participant to build on the conversation and explore topics as they emerged. Participants were prompted to share stories regarding their experience as a person living with HIV, treatment, adherence, patient-provider encounters, and trust. In addition, the grounded nature of the study offered topics central to the concerns of the participants be explored, resulting in emerging themes not initially considered. Interviews were conducted in person at the Tarrant County Health Department or the participant’s home, as well as over the phone. All interviews were audio recorded with the participant’s permission after a signed consent form was obtained. Interviews typically lasted about an hour.

3.6.1 Recruitment

Participants for interviews were recruited using a contact sheet included at the end of the survey. Additional interview participants were recruited directly through email contacts provided by the Planning Council.
3.7 Data Analysis: Grounded Theory and Mixed Methods

While quantitative approaches to data gathering and analysis are often a preferred method in that it tends to be quick and objective, this approach on its own tends to provide only a snapshot of the issues and potential solutions. By incorporating a qualitative aspect, the data gleaned through these surveys not only worked to help guide interviews, but were validated by participant testimonies.

Given the mixed-method nature of this study, data from quantitative and qualitative sources were initially analyzed separately and later combined to provide context. By using this approach not only were questions pertaining to the research answered, but moreover explanations as to why questions were being answered a certain way were captured through interviews. Insights gleaned through survey data worked to better guide interviews and uncover themes previously unidentified in the survey itself.

3.7.1 Quantitative Data

Surveys from patients and providers were collected separately. Data from these two surveys were entered into SPSS (V22.0). The descriptive data and results were used to guide the trajectory of the study and played an instrumental role in the evolution of interview protocol and questions.

3.7.2 Qualitative Data

Interviews were transcribed, and a line by line analysis was conducted. This analysis was used to code data into potential themes. The semi-structured nature of the
interview process resulted in a number of codes that overlapped between participants. From these converging codes, general themes were identified and became central to overall study results.
CHAPTER 4

RESULTS

4.1 Participant Demographics

A total of 76 participants were included in this study. Seventy-three of the participants took the survey, while 3 opted to only participate in the interview. Of the participants, 62 identified as Patients and 14 identified as Providers. A breakdown of demographic information is illustrated in Table 1.

Table 1: Participant Demographics

<table>
<thead>
<tr>
<th>Participant Demographics</th>
<th>Patient (n=62)</th>
<th>Provider (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age</td>
<td>49</td>
<td>51</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>54</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Transsexual</td>
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<td></td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>31</td>
<td>14</td>
</tr>
<tr>
<td>Black/African American</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Latin/Latin American</td>
<td>5</td>
<td></td>
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<td>Asian</td>
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<td></td>
</tr>
<tr>
<td>Biracial</td>
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<td></td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sexual Orientation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gay</td>
<td>43</td>
<td>2</td>
</tr>
<tr>
<td>Heterosexual</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Lesbian</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Bisexual</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
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<td>0</td>
</tr>
<tr>
<td>Missing</td>
<td>7</td>
<td>3</td>
</tr>
</tbody>
</table>
Of the 76 participants, 20 agreed to be interviewed. The data became saturated after 17 interviews when it became clear that pursuing further interviews would unlikely result in the discovery of additional themes.

Participant surveys were coded based on whether one identified as a Provider or a Patient. To answer the research questions, participants were asked questions regarding the importance of trust, the role of communication, word choice, and barriers to adherence. Results from survey data were used to inform and guide participant interviews and worked as a mode to interpret overall study results. By combining the results from both methods a more conversant interpretation of the data was achieved.

4.2 Reported Adherence

A total of 64 participants answered the section regarding treatment adherence (Patients, n=52; Providers, n=12). Patients were asked to report their current adherence, (On average, do you take your medication as prescribed) and Providers were asked what they perceived their patients’ treatment adherence was.

Figure 2: Reported Adherence Rates
The perception of treatment adherence differed among the two groups where the majority of Patients reported 100% adherence, while the majority of Providers reported current rates by their patients to be adherent to medications 75% of the time. For this question, Providers were asked to report an average adherence rate for all their patients, whereas patient data was individualized reporting. The complication in reporting treatment adherence is that a 100% adherence rate is a difficult goal to achieve, and while the Patients who reported that they adhere to treatment 100% of time, the reality is that there were times when they may have missed a dose. Sporadically missing a dose or not taking it on time is not an indicator of non-adherence, but a reality that providers understand.

A hundred percent? For real 100% or like in a real world 100%, like 98% or 99%...[an adherence rate of] about 95% is missing one pill in three months if you’re on a ‘one pill once a day’ regimen. It’s not like they are slacking. (PR02)

I ask every patient that I see, “In the last month, how many doses did you miss?” The answer is one, sometimes two. “And what was the circumstance?” “I got home from work very late. I was dog tired. I laid down and I went to sleep. I just forgot to take it.” Hey, that happens to me. I take blood pressure medicine. I miss more than one dose a month. And so when I hear excuses like that, hey, that’s 100% adherence. (PR03)

For some Patients the issue of adherence was seemingly uncompromising, while others acknowledged a missed dose every once in a while was just a fact of life.

I've been on it for let me see I think since March 2013, and I have never missed a dose...never not once...missed a dose so I am very, very, very compliant...with all meds especially that one [Atripla] and my blood pressure med. (PT01)

Very. 100%. I even set my alarm on my phone in case I go to sleep so I don’t miss my meds. (PT04)

I very seldom ever miss. There are occasions where I like fall asleep and wake up really early in the morning and it was like, well, this pill kind of makes me feel a little funky and drowsy and I have things I have to do that required driving. So
I'll go ahead and miss that dose but I make sure I take it the next earliest convenient before I go to bed that night. (PT03)

By exploring perceptions regarding adherence from both the patient and provider perspectives it is evident that Providers understand that there is no such thing as 100% adherence, however an occasional missed dose is not indicative of non-adherence. For some Patients adhering to treatment 100% of the time was a reality and offered that the measures they take in order to not miss a dose was a priority.

With a general understanding as to how perceptions regarding adherence were understood by both Patients and Providers themes from the interviews were identified.

4.3 Themes

Follow-up interviews from participants tended to mirror results from surveys, but yielded an opportunity to explore the issues further. A coding of transcribed interviews produced the 8 themes discussed below.

4.3.1 Age and Adherence

Age as it relates to adherence was expressed by both Patients and Providers. An interesting discovery was that perceptions of the impact of age on adherence tended to differ among the two groups. For Providers, age and adherence were conveyed as being related to maturity. PR01 articulated this perspective from the provider point of view citing that older patients tend to be more adherent to treatment because they are accustomed to taking medicines on a daily basis.

I think it depends on their age and where they are with their maturity level. Say someone who’s coming in for the first time and say they’re in their 30s or older, talking about medications and initiating treatment – I think maybe as we get older, we may see the doctor more often as people age. They’re on medications already and they are already taking medicines for this or for
that. It’s not so foreign to them about having to take medicines and they’re more likely going to adhere to a treatment regimen.

So I can have someone who is newly diagnosed, but it’s maybe someone in their late 30s. Putting them on medicines and having them stick to the regimen, we’re not going to have that big of a problem with them. They’re going to be for the most part overall adherent. Now if you’re talking to a youth between the ages of 17 to 24, you have a whole different ballgame. You literally are because it’s a struggle. They’re sitting in front of you saying, “Yes, I want to do what I need to do to take care of myself.” They have good intentions. They don’t have the intentions of like, “No, I’m not going to take meds and I’m not going to come to my doctor’s appointments.” They’re being real when they’re sitting there and talking to you. So they have the really good intentions of taking care of themselves, but they are the highest risk of folks dropping out of care. They’re the ones that drop out of care. We can’t keep them on their medications.

For this provider, age at time of diagnosis tended to be perceived as playing an instrumental role in treatment adherence. Similarly, PR02 offered that adherence was not only related to maturity, but also offered a physiological explanation:

We have a much, much harder time retaining, caring and keeping on treatment, especially with young men. 24 year old men or 20 year old men still think they are invincible. I mean, if you look developmentally where our brains are at that period in life, we're still in that period of space where we're like, “I can do anything. Nothing is ever going to happen to me.” It’s a period where the pleasure centers of our brain are more important than almost anything else.

Age, for patients was not an emphasis on maturity, but rather experience. All of the patients interviewed expressed their age in terms of how long they have had the disease, not how old they were. One patient even offered his diagnosis date as his “other” birthday, “July 17th, 1996 is my other birthday” (PT04). The mean age for patients interviewed was 49 and with one exception (PT06, diagnosed in 1982) all were diagnosed with HIV in the 1990s or early 2000s. For these patients, HIV and age was negotiated around being a survivor of an epidemic that took the lives of
many of their friends. This first-hand experience of the reality of the disease and its impact created a sense of urgency regarding the threat of one’s own mortality; however, this experience also offered claims regarding delaying treatment after diagnosis.

Early on in the disease, Azidothymidine (AZT) was prescribed as the main course for treatment, but it came with side-effects that were not only undesirable, but could be considered worse than the disease itself. PT04 reported that seeing his friends die from HIV was not a factor in making him adhere to treatment, but in fact played a role in why he delayed treatment for 10 years. “I watched them take their medicine and die, I could tell it was killing them…” The issue of side effects and adherence will be explored further, but for now this excerpt works to provide a context as to how age and experience may impact treatment adherence.

Age and adherence continued to emerge as a major theme through the context of experience. PR01 reported that newly diagnosed patients might not fully comprehend the impact of the disease, because they are too young to remember the history of HIV/AIDS. Furthermore, newly diagnosed patients may not have experienced the loss of friends and loved ones.

Our older folks that have been positive since the ’80s, they are the warriors. The HIV wiped out their communities. It wiped out their families, their friends. They saw what HIV and AIDS can do and it’s just horrible.

PT04 shared a similar sentiment in regards to the experience of those who have survived HIV versus those who have been recently diagnosed:
They should see us as heroes and ones that were their guinea pigs and we took the meds that, we died for them we fought for them, we threw bricks at courthouses, we did sit-ins, we did die in’s, we made quilts, we screamed and yelled and we got things changed, but they don’t know that, they don’t know the history…I heard one person say it’s an old person’s disease, we don’t have to worry about that anymore, and that really kinda made me mad. They didn’t have to go through all the funerals…I don’t go to funerals anymore, I stopped going when I was younger. I mean everyone I knew died back in the 80s.

4.3.2 Barriers to Adherence

Efforts to explore adherence cannot be considered without also exploring potential barriers. While there was a reporting of high adherence (75-100%; n=56) from both Patients and Providers, the way they perceived barriers tended to differ. Survey questions regarding barriers asked Patients and Providers to rank what they perceived the biggest barriers to their treatment on a scale of 1-10 with 1 being the biggest barrier. By controlling for those who reported a 100% adherence level, survey data found that perceived barriers for Patients and Providers differed. An interesting discovery was the potential disconnect between these groups regarding the barriers of “Time” and “Side-Effects” in which Patients had the highest frequency of responses while Providers had none. In addition “Communication with Provider” was also perceived as a bigger barrier among Patients than Providers, however because this emerged as a theme central to this paper further discussion will be reserved.

Figure 3 illustrates a number of perceived barriers, and while all are relevant to this study, some emerged as being more prevalent themes.
4.3.2.1 Side-Effects

Patients who have lived with HIV for a longer period of time, or who may be more aware of its history as a disease, tended to consider side-effects of HIV medicines as a barrier to adherence more so than their younger counter-parts. While the younger demographic was not captured in this study, experiences from those who were once “the young” are captured. PT07, a patient who has been HIV positive since the early 1990s reported:

Man, I’ll tell you what...if you took those meds, you were going to die...they’d kill you faster than the HIV...AZT was bad...back then HIV was a death sentence if
you took your meds you were fucked, if you didn’t take your meds you were told you were fucked, but seeing so many of my friends shit their pants and hanging out on the edge of toilet seat puking their brains out...that’s not life, I’d rather take my chances…and I’m here, they’re not.

All patients interviewed in this study made a reference to AZT at one point. It was from this a connection regarding the side-effects was made. AZT continues to be prescribed and appears to contribute to a reluctance to adhere to the treatment prescribed by their doctor in the early stages of diagnosis. Given the age of participants and length of those living with the disease, a case for lack of adherence could be made. With that being said, these survivor stories offered that certain pharmaceutical advancements in limiting the side-effects and number of pills taken may have played a role in their willingness to take the medication prescribed.

You know back in ’98, I was on a cocktail where I was taking like 20 pills a day…and they made me feel like crap…I couldn’t handle it…now I take two pills a day, it’s more manageable, but they’re just bigger, these new pills are huge…they combined different meds into 1 pill, so I’m taking two different pills, but It’s like swallowing a horse pill…but at least it’s just once a day and they don’t make me as nauseas, but sometimes it feels like it’s just stuck in your throat all day long...they are huge. (PT07)

An additional difference in the perception of side-effects can be viewed in an experience recounted by PT02, following a question which asked him to recount an experience with a provider where he directly confronted a provider regarding concerns about side-effects:

She made this comment...that and I think she made it in a positive way, but she...the way I heard it didn't sound positive...the way I heard it in a nutshell...she said “people that have side-effects, I mean it’s terrible that they have side-effects, but there is another possibility to not having the side-effects, I mean just think of if the medicine didn't work for you....and you wound up dead...” I mean she was basically saying you should be thankful that you at least have the drug even with the side-effects...that’s what she was saying...because you’re alive...
Me: How'd that make you feel?

PT02: It was almost like, like I said like someone hit me in the face with a pan… it was almost like I should be thankful to be alive…it was almost like…it was just callous the way it came across. And I don't think she was trying to be hurtful when she said that...

PR03 shared an almost identical awareness regarding approaches that providers take when discussing side-effects with patients: “Some providers, they say: Well, hey you feel bad? You got to be alive to have complications.”

It should be noted that PT02 continued this conversation by stating that he and the mentioned provider in this situation currently have a great relationship, and as such, this excerpt should not be taken out of context. However, for the purposes of this study, this selection works to illustrate a potential disconnect between the patient and provider in regards to conversations regarding side-effects. A general finding during the interviews was that Providers tended to regard side-effects associated with current HIV medication as being minimal when compared to the side-effects experienced in the past. This awareness was also echoed by patients, where a genuine concern surrounding side-effects remained salient throughout many of the interviews. It was discovered was that Patients reported a perceived belief that their providers tended to associate side-effects as a barrier of the past, or a symptom they should welcome because it proves they are alive.

PR03 offered the provider perspective in regards to how he approaches concerns regarding side-effects:

I’m very quick to explore side-effects from the medication because there are times when people stop – and I usually tell people upfront, “Look at this. We’ve
got 35 different medications we can use. Some of them will make you definitely sick and some of them, you won't even know you're taking anything."

And so I'm a person that changes the medicine regularly. I want you to be on a program that you don't even know you're taking or you take a pill and absolutely nothing happens and you feel fine. If you feel fine taking my medicine, you're not going to stop taking it. But if you feel bad taking my medicine, then the bad feelings are going to accumulate and become intense. And gradually, you're going to develop very negative feelings about taking the medication. You're going to postpone taking the medication and then you're going to skip taking the medication and then you're going to stop taking the medication.

So I say, "If you don't like my medication, come back and tell me. It will not hurt my feelings. You are not taking this medication for me. You're taking the medication for you."

And so my goal in therapy is to get you a set of medication that you don't mind taking. I want to get you a set of pills that don't make you sick, that don't make you feel bad in any way. "And so, if for any reason, you don't like my medication, come back and see me immediately and we'll change it to something else."

I have that conversation with every patient. And so, therefore, if you stop taking my medication, you know that it's not because I'm unwilling to change. It is because you failed to come back and talk to me about it when I created that opportunity for it...now some providers don't do that [switch medications because of side effects], "Well, hey, you feel bad? You got to be alive to have complications." That's not an answer at all.

For PR03, a Provider who has been treating HIV-positive patients for over 20 years, an awareness regarding side-effects both past and present remains central to his conversations with his patients. This excerpt works to illustrate how patient and provider concordance regarding treatment is negotiated. PR03 extends some of the responsibility on the patient, by suggesting that he openly welcomes feedback and if the patient does not provide that feedback then at some point the patient bares the responsibility. This excerpt also works to support previous concerns made by Patients in this study regarding how some providers dismiss their concerns regarding side-effects.
4.3.2.2 Mental Health and Substance Abuse

When directly questioned about barriers during interviews, Providers unanimously declared that substance abuse and mental health issues as being the biggest barriers. “Substance use…Untreated mental health issues. They tend to go together. So it can be a little hard to separate out” (PR02). PR02’s response was echoed in responses from multiple providers such as PR01 who in a heartfelt response offered that:

The majority of people who are not going to follow through on their treatment are going to be those that have those social problems, maybe their age group—their maturity level. The people who have chemical dependencies, these are the ones that we see that aren’t going to follow through…We screen all of our patients when they come in at each visit for substance abuse, for alcohol and the majority of people, they’re going—I would say the majority of people that I see, they screen positive for having a problem with drugs or alcohol. And they would benefit from the referral. But what I see the most is that not everybody is ready to address it. Just because they’re using drugs doesn’t mean that they think that they have a problem. They’re not even at the stages of change. They’re not even at the contemplation stage. They’re not there yet. So we still start them on medications anyway.

PR01’s response to the question regarding barriers acknowledges that a holistic approach to treatment would be ideal, but it also inferred that a patient’s willingness to accept treatment for issues that fall outside the scope of HIV was met with resistance. This evolved as an important theme to be considered because often substance abuse and treatment adherence tend to be reported as being positively correlated and have even been considered as a precursor in a provider’s perception regarding treatment adherence (Reynolds et al. 2004).

You got someone who’s addicted to drugs or they’re heavy heroin user or they are this or that and they’re not going to take their meds… I can tell you what we do in our clinic. We treat people regardless. (PR01)
The Provider perspective offered during the interviews suggested that while drug abuse constituted a barrier, the mental health issues commonly associated with treatment non-adherence were not as easily teased out. This may be in part due to that substance abuse is screened for and thus easily verified, whereas mental health issues may have extended beyond the scope of the Provider’s expertise and professional license.

Given the association of mental health and substance abuse, during the interview, I asked Providers whether they felt these issues preceded the HIV diagnosis or evolved as a result of it. While most Providers interviewed offered it was a mitigating factor that led to the initial contraction, there was an awareness that following a diagnosis these may be amplified. Here is an example regarding substance abuse:

You know, I had one patient, her husband had just died from pneumonia, and he was young…she was sitting there asking the nurse how someone who was so young could die from pneumonia and the nurse said “Well it’s more common than you think with HIV positive patients.” So here I have a lady whose husband just died, who just found out her husband of 5 years had HIV and never told her, and now she finds out she’s HIV positive. It was a triple whammy, you know if that was me I’d start using drugs, imagine processing all of that at once… (PR08)

While Patients reported a higher awareness regarding the impact of substance abuse and mental health issues on treatment adherence in the survey, Providers tended to suggest that these two barriers were related during interviews. The fact that Patients tended to perceive substance abuse as a more influencing factor in regards to barriers than Providers should not infer there is a correlation, but rather a consciousness regarding a self-awareness of barriers.

4.3.2.3 Medication Schedule/Too Many Pills

For Patients the medication schedule and number of pills they take a day presented as a barrier. It was not until the interview process that I discovered that this
barrier was not related to HIV specific medication, but rather a combination of medications they take for other medical conditions.

Me: How many pills are you on now?

PT03: I would probably say I'm on anywhere between…close to 15.

Me: And are those all for HIV treatment...

PT03: No. I only have 1 HIV med and that's a 3 in 1 pill. Everything else is for high blood pressure, hypertension, Neuropathy, insulin for the diabetes, and water pills, 2 different types of water pills that fall with the diabetes. And it's like, "Oh, yikes." It sucks.

PT03’s experience with having to take multiple pills to address co-morbidities is something that HIV specific providers should remain aware of when considering potential barriers to adherence. The fact that HIV treatment regimens have improved does not necessarily imply the number of pills a patient takes a day have reduced. This is an issue that will likely increase in importance as those living with HIV and AIDS are living longer and are experiencing the same age related issues as others.

4.3.3 Time

“Time” as a construct emerged as a theme initially identified in the survey and continued to develop during the interview process. Survey analysis immediately suggested that patients placed a high value on “time” as a major barrier in adherence, particularly when compared to providers. Additionally, “Time” as a theme evolved in such a way that it became clear the value and definition of time differed between these two groups.

“Time” was identified as barrier to adherence by patients in the survey however failed to elicit the same response during the interview process. This discrepancy is best
explained by highlighting the role that the semi-structured nature of interview process played in teasing out what the “Time” meant to the participants. “Time” as a barrier was not identified as being related to the patient’s adherence, but rather the time associated with appointments.

I know they are busy, but I have shit I need to do too. Hell, I know there’s a lot of us, but when I come in and there’s no one else waiting to be seen, It’s just like, why the hell are they behind schedule…no one is here…it doesn’t make sense. (PT07)

PT07’s response, while seemingly confrontational, was followed with an understanding that some patients may require more time than others. For PT07 this understanding was limited in that it was perceived that an empty waiting room offered that appointments where on schedule and failure to be seen in a timely manner was frustrating.

Like Patients, Providers tended to identify time as being associated with scheduling; 70% of the Providers (n=13) that filled out the survey reported that they did not feel they had enough time to spend with patients as they would like. With an average time of 30-45 minutes per patient, Providers offered that there were times when some patients may require more time than others and sometimes the allotted appointment block for each patient was insufficient. PR03 mentioned the following when asked about how much time he spends with a patient:

As much as I want to. In an 8-hour period, I’m scheduled to see nine patients. So usually, I’m given 45 minutes and a new patient, an hour and a half. Almost never do I use all of the time because we are all satisfied. And one of the last questions I ask a person – I’m asking them a lot of questions, but the last question I ask them is, “Now, are there some questions that you have that you might want to ask me?” That sometimes leads to five more minutes’ of conversation, sometimes 15 more minutes’ of conversation. Sometimes, it leads to half an hour because as people get confidence, they will then sometimes say, “Well, you know, there is something that I’ve been wondering about. This has been in my mind for a long time. It’s something about HIV that I don’t understand.
Would you tell me about this?” Then I can go into a detailed explanation that satisfies them.

The time that PR03 affords his patients may be a welcoming experience for most patients, it also might serve as an inconvenience for those waiting to be seen. Finding a balance between addressing patient concerns and maintaining a heavy patient caseload is a skill that weighs heavy on providers, but is ultimately felt by those waiting to be seen:

They have such a case load …I think they get like 20 minutes per person…but I come in with my own notes of things I would like to discuss and what's wrong and so I know what I'm going to talk about…and because of their caseloads, their heavy caseloads they really can't just stay there and just chat, you know and I understand that perfectly, but a lot of people want your physician to be your friend and I'll always say that guy didn't go to medical school to be your friend, he went to be your physician… there was a physician we had I had when I first became positive but I think I only saw him twice, but he would answer peoples questions and he would see people for like two hours, which people loved… but I mean if you had a 12 o'clock appointment you may not get to see him until like 2 and that pushed the person at 2 back to 4 and you might…4 might not get out until 6 and everybody else just hated it, and I think that's just unfair to everybody else but some people really love that kind of thing because you can just sit and chat and chat and chat and chat…I understand, but you have to respect the next person coming along, they're just as important if not more so then you, you know, their issues and questions whatever and you got to give them their chance too, so just sitting there BS'ing making up things as you go along just ain't going to work. (PT01)

For PT01, an understanding regarding the importance of the patient encounter was apparent; however, an inability to find a balance within a scheduled appointment time presented an issue. For this patient, by coming into an appointment being prepared with a list of concerns, he had compiled over the last 3-6 months was perceived to help expedite communication with his provider, while it may have in fact hindered it. PR01 offers that while patients who tend to be more engaged in their treatment, those coming
into an appointment with a list of problems/concerns might create a time issue on the side of the provider:

We don’t have all the time in the world to answer all 20 questions. You come in with 20 problems and we only have a little bit of time. We’re going to cut you off and we’re going to say, “You need to schedule another appointment to address these.” And that’s going to piss you off. That’s going to make you feel like we don’t have time for you.

In this instance the patient feels that by saving a list of concerns over 3-6 months works to ease the burden on the provider by “cutting to the chase” during their scheduled appointment; however, the provider perspective offers that by forgoing communication between scheduled appointments the patient may in fact be contributing to prolonged wait times. By identifying this disconnect, certain measures can be taken to better address a balance between issues that may present prior to scheduled appointments.

4.3.4 Provider Qualities

Provider qualities emerged as a salient theme throughout this study in that it was a co-occurring theme previously discussed in themes such as Age, Barriers, and Side-Effects, and Time. In this section participants were asked to rank the most important qualities for a provider to have in order to establish trust on a scale of 1-10 with 1 being “very important”. A notable discovery was the perceived value that Patients and Providers placed on qualities of a provider in regards to trust. Typically research focuses on age, race, and gender as the central components of provider qualities. While this study included these variables, other qualities were researched to investigate additional issues related to patient and provider communication.
The two strongest qualities reported by survey participants were “take time to get to know patient” and “use words everyone can understand” (See Figure 4).

4.3.4.1 Take Time to Get to Know Patient

To elaborate as to how “take time to get to know patient” differed among Patients and Providers excerpts from the interviews are provided:

PT02: You know when I see my Nurse Practitioner she's in the room for at least 30 minutes I mean she's not coming and going she's in there talking to me she's asking me about my job at the [omitted] I mean she's just asking me random just trivial stuff I mean she seems involved. I can just say one word and she'll say, “oh you mentioned that the last time you were here” and she seems like she really heard me the last time I was here so I mean, I think it's really what's the word, I think it's really personalized I don't feel like I'm just a number when I go there I feel like she knows that I'm [omitted] and that I work at [omitted] and that I had this problem last time and she remembered about it type thing.
For PT02 this experience shaped his clinical reality in that he did not feel like he was “just a number” but that he was a person, and moreover that his provider saw him as such. Another patient perspective was offered by PT01:

…because of their caseloads, their heavy caseloads they really can’t just stay there and just chat, you know and I understand that perfectly but a lot of people, once again we’ve had this talk in meetings like for your physician to be your friend and I'll always say they guy didn't go to medical school to be your friend, he went to be your physician…

Interestingly enough as the interview progressed with PT01, he was asked to recount a positive experience with a provider in which he shared a moment when he was feeling depressed:

I didn't even know it was that noticeable but even the nurses that were there that have seen me for a long long time noticed that I wasn't...that my personality was different but they didn't know why. The doctor knew why, that was the only person that knew why...

Despite PT01’s initial assertion that the patient-provider relationship was perceived as being something strictly professional, an awareness regarding the changes in his personality were apparent, suggesting that at some point his providers had taken the time to get to know him.

Getting to know a patient is not always restricted to an office visit, for example PT02 shared:

[My Provider] she actually goes out of her way to learn even more then she’s learned in the medical school or something but she goes to like the Positive Voices meeting from time to time and she goes to these physicians lectures that they have at this church down the street from here and um she's done stuff that leads me to believe she’s invested in this more than just her, you know just a source of income I think, and she's um she's a heterosexual woman and she's gone out of her way to learn more about gay lingo, and all that other stuff and you know, about gay sex practices and stuff and you know she can tell some stuff about gay sex that I didn't even know....so I mean she seems like she’s
really invested in not just my recovery, but my thriving, that I thrive, so I'm really glad that she came along.

For PT02, his provider's dedication to learning more about his lifestyle and culture was perceived as a building block in their relationship; he recognized that her interests in his health were genuine and were not something she was doing because she was getting paid.

The above Patient excerpts work to illustrate the value that they place on a provider's commitment to take the time to get to know them. This time is not necessarily reflected by the number of minutes per visit, but the value of that visit.

In contrast, for Providers, the “getting to know you time” did seem to focus on the amount of time spent with patients.

[We have this one Provider]... It can take up to 45 minutes or even longer for a visit. But she’s going to chitchat with you. She’s going to come in and she’s going to say, “Oh, how is your dog doing?” And she’s going to give you all the warm and fuzzy feelings and everybody loves [her]. And then after you chitchat for a while, then you’ll get into your visit.

Our doctors on the other hand are a little bit different. [The Provider mentioned above] is very holistic. Not that our doctors aren’t… they come in and there’s just a different kind of bedside manner. It’s not that they are rude, it’s not that they don’t have time for you, but it’s just a different kind of style and patients may not be used to that. And they may say, “Well, she seemed rush” or “She was saying this and I really didn’t understand and I wasn’t comfortable speaking up.”

And so that’s why it’s really important for the case managers or the patient navigators to go in after their visit, especially when you’re new just to make sure that you’re understanding what your plan of care is, that you had a good relationship with your doctor, that you felt comfortable with your doctor because that ultimately is going to impact your care and whether or not you come back (PR01).

Ultimately strategies involving patient and provider communication shift based on the situation or the patient. “Personal” communication strategies appear to be more
effective when establishing a new relationship and when the patient is adhering to treatment and remains in good health. However not all Patients perceived the “Take time to get to know you” or personal approach as being important because they felt it unnecessarily prolonged appointment times in which scheduled appointment times were not met.

This patient perspective is interesting because providers have traditionally been criticized for not spending enough time with patients (Beach, Keruly, and Moore 2006; Skirbekk et al. 2011; Kao et al. 1998; Davenport 2000)

4.3.4.2 Words Used by Providers

Using words that could be easily understood was identified as a variable considered to be an important quality in providers in order to establish trust for both Patients and Providers in the survey. To explore how words impact treatment adherence Patients were asked “How do the Words Used by your Providers Impact your Treatment Adherence?” (Figure 5).
The results illustrated in Figure 5, show that the words used by their providers positively impacted Patients’ adherence. To better elaborate as to how this translated into adherence rates a cross tabular analysis was performed (see Figure 6).
By comparing the results from these two figures it becomes clear that words play a role in impacting treatment adherence, however patient-provider communication is not limited to words and develops as trust is established. This trust has been reported as being associated with shared experiences based on age, race, gender, and sexual orientation (Arnold, Rebchook, and Kegeles 2014; Singer and Marxuach-Rodriquez 1996; Dardick and Grady 1980; Dorsen 2014; Bonvicini and Perlin 2003; Luchetta 1999;

4.3.4.3 Age, Race, Gender, and Sexual Orientation

The age, race, gender, and sexual orientation of a provider did not appear to present as important provider qualities as much as the above mentioned qualities. However, it can be seen that Providers tended to identify race and gender as being more important when compared to patients (See Figure 4).

This difference in perception was well documented throughout the interview process.

We’re all women. In our clinic, we’re all straight women. And I hate that, but we are. And we’re all middle aged straight women, with one man. And so it’s like, “You know what? We really don’t have a good mix of people in our clinic unfortunately. (PR01)

Similarly, PR03 recounted an experience with a patient in which he perceived his inability to connect with the patient was based on his attributes as a provider:

This gentleman was a young, black, gay male and I’m an old, white, straight male. And so, I’m not sure that he takes me very seriously. If there had been a young black provider here that maybe understood his circumstance better, maybe understood his language better, maybe understood what kind of words to use that would create a feeling of urgency, that would create a feeling of necessity, that would create a feeling of sincerity, create a feeling of concern, that could communicate better than I can, maybe that would’ve been easier. Maybe things would’ve worked better from the start.

Being of similar race, gender and sexual orientation of a provider rarely emerged as a topic during patient interviews, suggesting that Providers might have a tendency to perceive this as more of an issue than patients do.

Age did emerge as an issue for Patients during the interview process:
Well, he is extremely old. He's maybe 70, almost 80 years old. And I have a problem with the provider not remember who I am, like you're my doctor and I've just seen you 2 weeks ago and you don't remember anything that we dealt with 2 weeks ago. So I have a problem with that...and he's extremely old, even though he's been there a long time and he's very well noted, but I think his age, I think there should be an age limit where you allow people to practice especially if you can't remember who your patients are.

Interviewer: Do you think the fact that he didn't remember you was because he was old or just that he has a lot of patients?

PT08: I do believe that his age is a factor...I just think that your memory ... I think he's almost 80, if he's not that. And I think that during those years your mind, things could happen with your memory. It's just, I know they love them, but I think that age is just too much, too much for a person that age.

Given PT08’s expressed concern regarding the age of his providers I probed further:

Interviewer: Is it important for you to have somebody that's the same age?

PT08: Yeah, or close to the age because then they understand young people, they understand the things that you go through. So my case worker knows what to ask for, and why you're there. She knows and understands everything that you do ‘cause she's our age. So she knows everything to ask you for... she will ask you things that you might not know or tell you things that you might know. So that the case workers are age appropriate to the people that they do, I just have a blessed case worker where she's my age, so we're able to relate on a lot of things.

PT08’s experience with his providers was insightful because it stood in stark contrast to survey results and earlier interviews I had had with Providers. While generally Providers spoke to age difference as a variable that concerned them, at no point was their age presented in which they felt their mental facilities were compromised. Earlier examples offered their acknowledgement of their age difference as something that was a perceived barrier in their ability to establish trust with their younger patients. However, as PR03, a 72 year old male provider...
with over 20 years of experience in the field of HIV treatment went on to explain, his age tended to work in his favor:

    I think it turns out that the middle aged and the older aging gay men, they’re just delighted that I am [here] in the clinic because we can kind of talk man to man.

In this instance PR03’s comments referring to provider qualities are seemingly contradicted in that previously he had made reference to his age, race, and sexual orientation as a straight man as being factors during the patient encounter as it relates to trust, but here the important factor is the context of the conversation. At this point in the interview, he was describing that as being the only male provider in the clinic he might be able to relate to their patients better.

4.3.5 Experience

    As I interviewed more participants, I discovered that age became more relevant when placed within the context of HIV as a disease, and more importantly, one’s experience with it. For patients, experience tended to revolve around how long they have had the disease, how long their providers have been treating the disease, and provider turnover. To explore this further I began to delve deeper and probed participants more as to potential provider qualities not addressed in the survey. Take for instance PT04, who offered that a disconnect was felt because the “age” difference between him and his providers was not so much related to the age of the provider, but their experience.

    I’ve had HIV longer than most of them have been alive… Because of my age, you hear a lot of repeating what they learned, repeating what they’ve read, repeating what they read in books. Just repeating back what they’ve read without really knowing all the things I know from back here...they just repeat what the book says…I’m not implying that they’re not intelligent or not knowledgeable,
just that some of them have just gotten out of school and have only been studying it for a year. I’ve studied it for 38 years. When I try to explain to them how my body reacts to medicine, that I don’t need a handful of pills— that I’m not going to take them. They say, oh no you can’t do that, “studies say”… But I’m a study sitting right in front of them! I study my own health, my own body. I don’t care what your study says. My body and mind tell me this, and it works well for me

PT04, was first diagnosed with HIV in 1982 and reports an adherence level of 85% and has an undetectable viral load. For this Patient his reluctance to take the advice of providers he feels have an inadequate experience to handle his HIV tells the experience of the patient and their perceived experience of the provider. PT06 later went on to explain how it was a provider’s experience, not their age that made him trust a provider:

...after talking for 15 minutes I was like oh my God...you understand what you’re talking about...can you be my doctor...and he was going “No, I got to many people with me right now.” But just hearing him speak I knew he wasn’t just repeating what he read.

For PT06 there was a perception of experience that made him immediately trust that provider after only 15 minutes, which speaks to provider experience as being a factor that should be considered when exploring adherence

4.3.6 Stigma

Stigma emerged as a major theme throughout the course of this study, because I explored associations of HIV stereotypes and how it impacted patient-provider relationships. Given that HIV is commonly associated with gay men (Kraft et al. 2000; Lieb et al. 2007; CDC 2015; CDC 2014), I looked to see if there were potential barriers regarding homophobia. While Patients reported that having a provider of the same sexual orientation was more important in order to establish
trust than Providers did (see Figure 4) this did not present during interviews with participants. “You just can’t be homophobic and be in this field… we identify you the way you want to. And all of our doctors are very, very good about that.” (PR01). This was repeated in all of the interviews I conducted regardless of Patient or Provider grouping; however PT04, a straight HIV-positive male who acquired HIV through heterosexual contact, did infer that being a male with HIV comes with labels:

When someone comes into the group [a local support group] up there that I know, I try to make them feel comfortable. Especially like straight guys. Because I totally get it – totally get it, because you don’t know what they’ve heard. You don’t know what people have said behind their back. You don’t know what they’ve seen on social feeds. People can be very, very cruel. Human beings are capable of some of the most atrocious things. I hate that they stereotype everybody and try to put everybody in the same box. Not everybody that has HIV is LGBT. It’s all different, but it’s all the same. A lot of straight guys get it from drug abuse, some get it from me, I mean not from me – the way I did. And when I got it, they weren’t sure that a guy could get it from a girl by doing oral sex on a girl.

PT04’s encounter speaks to the homosexual default that is often associated with HIV and the stigma it may bring with it. While the country as a whole has made great strides in addressing homophobia through legislation and policy changes, these changes may not have worked to create a full cultural shift regarding the stigma attached to being labeled as someone who is a member of the LGBT community. They continue to encounter discrimination. Take for instance this excerpt from an interview with PT08:

Interviewer: Do you think that in your experience as an African American male that there’s a higher stigma for HIV in that community?

PT08: Yes, it’s very much a stigma. I am in ministry and even to get leadership in the churches has been an issue. I think it’s still seen as a
homosexual disease, it's still very much so. And I think that it's still because
the MSM population is still at the top. But it is still seen as a gay man's
disease...I think that also the shift of HIV and AIDS in the African American
community really shifted between I want to say 97 and 2003, where it just really
shifted over into the African American community. And so we're just now really
playing catch up to where it really started to affect our community... and then we
had to find messages to fit our culture, the leadership to even deal with it has
been very poor.

PT08’s perception of HIV within his community speaks to the reported difficulty in
reaching the African-American community in regards to HIV prevention
interventions and patient engagement (Phillips et al. 2011; Coleman et al. 2009;
Wolitski et al. 2006; Kraft et al. 2000; Harawa et al. 2013). PT08 as a self-identified
African-American Man who has sex with men (MSM) introduced HIV as being
associated with being a “gay man’s disease” without any prompting.

It should be noted that while Providers dismissed homophobia as a stigma
within the context of the patient-provider encounter, there was little conversation
regarding the fact that patients may feel this stigma in their personal lives. When
asked to speak to the issue of stigma, Providers pointed to HIV as being the
biggest issue. Through my interviews I learned that once a patient tests positive for
HIV they are generally referred to an HIV specialist, who then tends to take on
most of their healthcare needs. However people with HIV have other health
problems just like everyone else. In situations where these health problems fall
outside of the scope of their HIV specialist referrals to other physicians are made.
It was in this referral process that Providers reported that stigma became an issue:

I do have a patient. He is straight, but he has AIDS and we had referred him
to an orthopedic specialist. We referred him to someone and he went there.
And he was referred to a doctor here in Fort Worth, just up the road. He was like, “Oh my god. What did you say? You have AIDS? No, we can’t work on you.” And when he [the patient] told me that, I said, “You have got to be kidding me.” I mean this is not in a rural area, a physician in a rural area. It’s Fort Worth.

This excerpt is one of many in which Providers spoke to a continuing fear within the medical community regarding HIV—a sentiment that was shared by patients, who feel pigeon-holed into a health care system where their disease takes center stage.

4.3.7 Funding

Providers surveyed and interviewed throughout the course of this study offered or received funding through government programs such as Ryan White. All patients interviewed (n=9) were receiving some form of governmentally funded insurance programs (Medicaid, Medicare) or through services provided through government supported grants, and with one exception all Providers (n=7) reported their funding for the services offered came in the form of grants. Funding came to emerge as a theme solely through the interview process, as it was not introduced in the initial survey.

PT04, who is currently on Medicaid looked at expanding his treatment options under the Affordable Care Act:

I really, really wanted to do this healthcare thing that they came up with, with the insurance. Wanted to real bad because for all this time, I kind of felt I was leeching on the system. Not carrying my load…so I picked the silver program that I could pay for myself and preexisting was supposed to be covered and all this. So I get all my forms done and everything done and I start digging at the exclusions, I start digging into the details and I find where, yeah, they’ll pay for my meds after the first $6,000. I live on $12,000 a year. I cannot go that route. And in order to get my other meds and be seen by other doctors and the system up there, if I have insurance they'll see me under insurance. But to pay for my meds, I'm under the Texas state med
program and have been forever. And if I have insurance, I lose my meds through the program.

Health insurance presents as a barrier for some patients because while they may have a larger pool of providers to choose from, certain deductibles are beyond their financial reach (Figure 6). With 41% of patients reporting a household of income of $20 thousand or less they may qualify for certain insurance programs, but by enrolling in them they may no longer qualify for services provided under certain HIV specific grants. The choice then becomes either stay with HIV specific funded clinics or pay more for private insurance.

Figure 7: Reported Household Income
One survey respondent stated “They are in government funded clinics and really don't care. You are just a number with no identity than a person on a lower economic status. You're a living number for funding”

For patients an awareness regarding how funding impacts their treatment was evident:

Everybody talks about how there was funding and every year it getting cut back more and more. But I know for a fact that – well, I didn't see it in writing, so I can't say it's a fact – but I've been led to believe that the money that was, that they usually allocated to us for the maintenance of that space up there went to smoking cessation for the county. And it's not bad enough that they built that whole wing of the clinic out there with Ryan White money, and then shut down 2-3 years later. Which really, as my friends in England say, has my knickers in a bunch. You know? I don't know how they pulled that off. (PT04)

...so many funds have been cut due to budget cuts that things are not available like they used to be like bus passes, even though I think they are, but not as like the toss of hat, and the food bank isn't full and overflowing like a cornucopia like it used to be there seems to be a lot of nostalgia for that sort of thing, but that's just a victim of budget cuts, you just have to deal with it. (PT01)

In addition, a dilemma that is often found was that clinics which are funded through HIV related grants come with a stipulation that all treatment and services provided should be HIV related. This stipulation in itself creates a pseudo-barrier to treatment adherence in that it dismisses health issues not specifically related to HIV, limiting a patient’s ability to discuss non HIV-related issues.

For Providers the issue of funding is a battle between paperwork, required meetings, and patient care. I had the opportunity to attend a meeting with healthcare providers/providers of services and the issue of paperwork was central to their conversation. This paperwork, a requirement stipulated by their funding
agency was referred to as burdensome, redundant, and ultimately took away from the time they could devote to their patients. During this meeting I observed a genuine desire to improve services for patients, a sentiment that was expressed by Patient Participants:

...that’s my only complaint about the system. Our case managers are overworked. They’re overworked by paperwork that they have to do…it’s just terrible. And they don’t have time to keep up with us. At some point somewhere, somebody needs to help them. (PT07)

4.3.8 Communication

The goal of this study was to explore the impact of Patient-Provider communication on HIV treatment adherence and as such it became the theme that ties all of the other themes together. While some aspects of communication have previously been discussed, this section ties together all of the discussion on communication. Communication is not limited to words or conversations, but also body language, inflections, and tones. Perceptions of communication tended to be subjective and catered to the audience. Providers offered that sometimes a gentle bedside manner was appropriate for some patients, but not for others. For example, a patient encounter recalled by PR03 who after multiple visits with a declining patient took on what he called a “brutal but frank” conversation:

...so if he hasn’t woken up, this may be his last visit here before he dies because when he gets sick that’s it...so then, I get even more brutal. I say, “You know, they sell caskets at Costco. You can save your relatives a very sad task here if you would just go pick out a casket and buy it and take it home. Why don’t you sleep in your casket” and I said, “They can come down in the morning and they can check to see if you feel cold and if so they can just close the lid and call the undertaker. At this point, he was crying, and then he said to me, “Can I double up on my medicine?”
That to me showed me that I somehow got through to him and he was now mustering some kind of resolve to take his medicine. He now wanted to get out of this jam much faster than I wanted him to. He wanted to go twice as fast as I wanted him to go. He was now willing to double up on his medication if that would get him out of the problem...I took that as being a positive sign. But I said, “No, if you double up on your medicine, it can become toxic to you. So I said, “Are you going to take your medicine?” and he said “Yes, I’m going to take my medicine.”

PR03’s approach to the situation with this particular patient was certainly not one that would be found in any current medical handbook, but after weighing that previous visits had little impact on the patient’s understanding of the importance of treatment adherence, the provider felt that an extreme approach would work better.

Approaches to patient and provider communication shifted between good bedside manner and brutal honesty. Providers expressed that it is not that one is better than another, but is situational. Providers offered a genuine self-awareness regarding their approaches to patient care.

I am a fairly straightforward person. Some people like people who are a little more, “Don’t tell me the hard things”...I try to be pretty soft with people, but I am not one of those people. I do not believe in not telling people the truth. If I know something is going on, I am going to tell people. I just believe that’s the right thing to do. And not everybody wants that.

Patients noted similar situations where responses regarding a preference to providers who took time to get to know them was seemingly mixed between the “personal” and “clinical” approaches as was previously discussed under Provider Qualities.

For the most part communication emerged as a theme that focused on the face-to-face encounter, however a section of the survey asked participants to add anything else they wanted to share regarding patient-provider communication. A
review of the comments resulted in some unexpected discoveries. For instance when I considered patient-provider communication I was focused on a clinical reality and failed to consider the role of communication outside of the clinic doors. A number of surveyed Patients suggested that more phone calls and emails would help to improve communication. Though this did not emerge as a co-occurring theme during interviews, it should be considered as a possible means to help improve communication between patients and providers.

4.3.8.1 Provider Communication Styles

In one interview a Patient reported that a “lie” made by a provider almost prevented him from seeking further treatment from a certain organization:

...Initially I was so angry...I caught her in two blatant lies and I wasn't going to go back and I went home and I was so enraged about it and I thought I'm just not even going to go back there anymore, and I thought why should I even go back there, and I told my mother about it and she said, and she calmed me down, which she can always do and she said don't let her steal your joy like that, like that don't let her win (PT01).

When I first got diagnosed, the way they bullied me, “You’ve got to do this, you’ve got to do that, you’ve got to call all these people. Who have you had sex with? How many times?” I mean, they’re just bullies...and you don’t need bullies when you just got diagnosed...you need understanding...it was just terrible...any kind of HIV or any kind of STD, you're bullied. “Who have you had sex with? Well, you got to call them. We want their names and phone numbers.” Their names and phone numbers. I mean, really? No. (PT07)

My first doctor was a cunt. I lost weight due to stress and she instantly accused me of using drugs... if the doctor is shaming you or looking down on your illness it can make you not want to get help. (PT03)

The fact that some patients encountered situations in which the words used by their providers’ elicited feelings of emotional pain or anger speaks to the impact that words can have.
4.4 Perceptions of Words

Foucauldian theory offers that words matter and that certainly became apparent during the course of this study (Foucault 1990). Building off of Good (1994) where perceptions of illness were argued to be subjective I asked participants their perceptions regarding a series of words.

4.4.1 Is HIV a Disease or an Illness?

When asked to identify if HIV is a disease or an illness a surprising result was that around 20% of participants interviewed identified HIV as an illness and not a disease. (Figure 9).

Figure 8: Is HIV a Disease or Illness?

Upon further exploration it became evident that the definition of HIV as a disease was not clearly defined. Interestingly enough, the DHHS offers that…If left
untreated, HIV can lead to the disease AIDS (acquired immunodeficiency syndrome)” (US Department of Health and Human Services 2015). Per this definition, HIV is not considered a disease, but AIDS is. By definition a chronic disease is a disease lasting three months or longer (CDC 2013). For all intents and purposes HIV would certainly qualify, but the delineation of HIV as a pre-cursor to a disease and not a disease in itself presents a certain degree of confusion. Take for instance this perspective offered by PT07:

PT07: People think HIV and AIDS are two different things, what they don’t understand is that they are not. HIV and AIDS are the same disease…it’s a calculation of a number that makes you have AIDS or just be HIV positive. AIDS is just a bad case of HIV…it’s a bad case of the flu…it’s a government calculation. If your CD4 count goes below 200 you have AIDS…so at one point my CD4 count went to zero, so then I really had it… I mean I’ve had AIDS 3 times.

Me: So what you’re saying is that once your CD4 count goes up you no longer have AIDS, is that what you are saying?

PT07: No…you always have AIDS…I mean my CD4 count has been 250, that’s kind of been my number….but once you have been diagnosed with AIDS you are permanently disabled with AIDS period. End of story.

PT07’s referring to AIDS as a “bad case of flu” may appear flippant, and his definition of HIV or AIDS as an arbitrary number is not without merit as changes in minimum CD4 counts as an indication of AIDS change as research continues to improve. Current measures indicate that once a person’s CD4 count falls below 200 they are classified as having AIDS, regardless of whether or not their CD4 count improves over time (AIDS.GOV 2015). For PT07 AIDS was just a bad a case of the Flu, but does that illustrate how people perceive the difference in a disease and an illness? In this study I asked Patient participants “What does the word the
“Disease” mean to you?” and “What does the word “Illness” mean to you?” A frequency table of responses can be found in Table 2:

Table 2: Perceptions of Disease and Illness

<table>
<thead>
<tr>
<th>Perceptions of Disease and Illness</th>
<th>Frequency Counts</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Disease</td>
</tr>
<tr>
<td>Chronic/Cannot be Cured</td>
<td>10</td>
</tr>
<tr>
<td>Death</td>
<td>4</td>
</tr>
<tr>
<td>Illness</td>
<td>4</td>
</tr>
<tr>
<td>Something you can live with</td>
<td>3</td>
</tr>
<tr>
<td>AIDS</td>
<td>1</td>
</tr>
<tr>
<td>HIV</td>
<td>2</td>
</tr>
<tr>
<td>Sick/Not feeling well</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>39</td>
</tr>
</tbody>
</table>

By looking at Table 2 it becomes apparent that survey participants perceived a difference in the words disease and illness. Disease was frequently perceived as something that was chronic or could not be cured, but only four people associated it with death. On the other hand when asked to define what illness meant to them it was frequently perceived as feeling sick or not feeling well. Being able to distinguish between these two perceptions might work to better improve adherence, in that for the most part patients who feel well do not feel a need to medicate.
PR03 shared an anecdote he had previously used with a patient who “felt fine” despite a decreasing CD4 count:

“I had a young gentleman who his CD4 count when he came to see me for the first visit was about 100. His viral load was high and I put him on medication. When he came back, his viral load was still high and the CD4 count had dropped from 100 down to about 50. We had a serious conversation and I stressed the importance of taking the medicine.

So he came back for his third visit – and you have to give him some credit because he kept coming back because there are people that we have that conversation with, we give them medication and they just never come back...But he did come back for his third visit. And on his third visit, his CD4 count, his immune system, it was less than 20. He had no detectable immune cells at all, none. And his viral load was high.

You have no immune system. Your chance of dying within the next year is very high, maybe as high as 30%, 40%, 50%.

So here is a young person who said very clearly, 'I feel good.' What do you say to someone who has absolutely no immune system who says, 'I feel good' who has come back three times – well, you have to be very innovative.

So I told him about a fellow who went to the top of the Empire State Building which is like 110 stories and he fell off. As he was plummeting toward earth, he went past the 32nd floor and somebody on the 32nd floor heard him say, Well, everything is alright so far.

I said, What does that story tell you?
He said, 'The guy is going to go splat.'
I said, Yes! But what he said in the 32nd floor was, I feel good. I said, that’s just what you told me. You just told me, I feel good. I said, you have no sensation of falling. But I know you have fallen past the 32nd floor. You’re down to the 10th floor.

Now, that may sound really brutal and it’s very frank, but not unreasonable nothing that has been said up to this point would wake him up. So if he hasn’t woken up, this may be his last visit here before he dies because when he gets sick, he’s going to go to the hospital and I’m not going to see him, and maybe they won’t be able to save his life.”

PR03 took on what he perceived to be a last ditch effort to reach his patient and get him to take his medication because he recognized that for this patient, not
“feeling sick” was the barrier that they needed to overcome. Similar stories were shared by other providers in which they encountered patients who refused/neglected to take their medication as prescribed because it was not a priority:

The most challenging thing to me is that I know what they need to do. This is awful. I know what they need to do and they don’t do it...I see them because I know about HIV resistance. I know the importance of taking your meds and what happens if you don’t take your meds, how you can become resistant to certain meds and even classes of meds...I see people who have so much potential. I don’t want to say they don’t care, but it’s just not a priority in their life yet...I can see them go downhill and you’re like, “But you got to do this. You’re circling the drain and we can’t pull you out. How many times are we going to pull you out? You’re dying. You’re going to kill yourself if you continue this way.” (PR01)

For Providers the sense of urgency was at times at a different level than their patients. “They’re not even at the stages of change. They’re not even at the contemplation stage. They’re not there yet.” (PR01). This increased sense of urgency on the part of the Provider could be attributed to their experience in treating patients with HIV or AIDS, whereas for Patients a sense of urgency is delayed because HIV is much more manageable than in the past.

4.4.1.1 HIV as a Chronic Disease

In subsequent interviews I asked both groups if they felt that HIV’s transition towards a chronic disease status has worked to minimize adherence. Patients and Providers both reported this as a concern. Both groups felt that the perceived severity surrounding an HIV diagnosis has been minimalized over the years. It was emphasized that newly diagnosed patients, or people who have never lost
someone to HIV or AIDS fail to understand the role that medication adherence plays in whether one lives or dies.

I wish my roommate was alive to talk to you...because he did, he's one of those persons, well he did everything wrong, it wasn't the providers fault, it wasn't the systems fault or anything...because he did everything wrong...and he so he basically committed suicide because he just wouldn't take...he was very much a free spirited person and he just wouldn't take his meds (PT01)

4.4.2 Is there a difference between HIV and AIDS?

Earlier PT07 suggested that there was no difference between HIV and AIDS, but rather it was an arbitrary number assigned by the government. Foucauldian theory supports this thought in that by assigning something a name it can be regulated (Foucault 1973; Foucault 1990). For PT07, the medical community has assigned a number to a CD4 count which would identify someone as having AIDS versus HIV, which in his opinion can change at any given time. Given that medical thresholds regarding HIV and AIDS have changed over time it became important to this study to explore perceptions of the values that people place on the labels. As this was an emerging theme it was not initially introduced in the survey, however the more people I spoke with, the more it became evident that HIV and AIDS were perceived very differently.

And I just think that even now I think that when you address just HIV, when you say the word HIV it's common, but when you say the word AIDS that is another ball game. That word right there just frightens a lot of people. It causes fear and hysteria when you say the word AIDS. You can say HIV comfortable, many people have HIV and they can deal with that. But the minute you say AIDS that is a different ball game. That word AIDS it's like another issue, a place on its own. (PT08)

...but she asked me did I have AIDS...she just asked me and I said yes...I didn't think to say “No. I have HIV”, I just said yes... (PT01)
I have not told my mom I am HIV-Positive, when I first told her I was gay her biggest fear was that I would get AIDS. It’s been about 10 years since I was diagnosed and I have been undetectable since the second year I found out, but she thinks it’s a death sentence...so, that’s why I won't tell her... She won’t try to get educated about it, it’s a generational gap and she is set in her ways. (PT03)

The word AIDS is scary for a lot of people, and really most of the patients I see do not have AIDS, they have HIV. (PR08)

For these respondents the stigma previously addressed between the words HIV and AIDS suggests that the way these words are perceived is very different. For PR03 the distinction is found in treatment adherence:

There aren’t very many AIDS deaths in Tarrant County every year. There’s less than 10 AIDS deaths in Tarrant County every year. Those who do die from AIDS died because they didn’t take their pills

Earlier themes demonstrated an awareness regarding a stigma associated with labels and while this topic could have been introduced at that point, I reserved it for this section in which it would deliver a greater impact.

Based on the results of this analysis I revisited the interview data to identify situations in which words used by providers might have the potential to adversely impact treatment adherence.

…it made me feel less than human when he told me....when he told me that if he found out I was molesting children he’d have to report me...it was like somebody had taken a cast iron skillet and whacked me in the face with it and it hurt so bad. (PT02)

For PT02, the words used by his provider were not specific to his HIV status but were premised on his being a gay man and the unwarranted association of pedophilia as being a practice perpetuated by gay men. While PT02 reported a
strong ongoing relationship with the mentioned provider, the tears building up as he shared this experience were not lost on me as researcher.

4.4.3 Adherence or Compliance?

Words do impress a degree of importance on patients. Sometimes the words “adherence” and “compliance” are used interchangeably. Roberson (1992) initially offered a distinction between the two based on a patient's perspective. Building off the research of Roberson (1992) I sought to explore if this remained relevant. In this study Patients were asked: “What does the word Adherence mean to you? And “What does the Word Comply mean to you?” A frequency chart of the responses from participants is shown in Table 3:

Table 3: Perceptions of Adherence and Compliance

<table>
<thead>
<tr>
<th></th>
<th>Frequency Counts</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adherence</td>
</tr>
<tr>
<td>Comply</td>
<td>8</td>
</tr>
<tr>
<td>Adhere</td>
<td>0</td>
</tr>
<tr>
<td>Obey</td>
<td>5</td>
</tr>
<tr>
<td>Follow</td>
<td>11</td>
</tr>
<tr>
<td>Stick to</td>
<td>7</td>
</tr>
<tr>
<td>Regular</td>
<td>1</td>
</tr>
<tr>
<td>Agree</td>
<td>1</td>
</tr>
<tr>
<td>Commit</td>
<td>0</td>
</tr>
<tr>
<td>Take Meds</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>39</td>
</tr>
</tbody>
</table>
Overall, for participants in this study it appears that an understanding of the words “adhere” and “comply” are interchangeable, which supports the by findings Roberson (1992). However, findings in this study suggest the word “Compliance” may tend to stress the authoritative role that providers have with words such as “Obey”, “Follow”, and “Take” appearing at a higher frequency. Much like Roberson (1992) reported these words are subjective in nature and while compliance had a perceived value of being more authoritative there was no indication that one word came across as being more influential than the other. Providers interviewed generally reported that they do not use these words during the patient encounter but shared similar responses regarding perceived meanings:

Let’s see. To adhere to something is to maybe set up in front of you and you accept it and you follow it. To comply is to be told something and do it. I don’t use those words usually. I just ask them to take their meds.” (PR02)

PR02’s response to the question mirrored those found in the Patient survey, however also offered that as a Provider she does not tell her patients what to do, but rather asks. Asking a patient to take their medication, rather than telling them they “have to” or “must” appears to represent a shift in the power dynamic previously associated with the patient-provider relationship.

Patients and Providers alike reported similar associations between these two words which shows that in this instance word choice was not a factor. Moreover, given that no relative difference in these words was perceived by Patients and Providers, there is no evidence suggesting that providers use the word “comply” as a tool to exert influences of power on a patient.
CHAPTER 5
CONCLUSION AND DISCUSSION

Words are instruments of power, not only are they perceived in different ways, but sometimes come with unintended stigmas or associations. Take for instance the vague distinction between HIV and AIDS as being a disease or an illness when compared to the value that is placed on the word “AIDS” versus “HIV.” Throughout the course of this study a focus on words has been central to discovering the impact of patient-provider communication on treatment adherence. In order to fully understand the role that communication plays in a patient’s treatment adherence it became important to explore issues related to patient-provider trust, communication, and the patient-provider relationship. Exploring this triad of care eventually resulted in a better understanding of how adherence is integrated within these overarching discussions.

The majority of the analysis for this study was devoted to exploring themes that answered the proposed research questions. By doing so the research questions where not only answered, but through an analysis of responses offered a better understanding was found.

I explored multiple explanations regarding treatment adherence. An initial investigation looked at the overall reported adherence for the participants in this study. While Patients self-reported, Providers reported an average of their patients adherence rates. With this established, barriers to adherence were addressed. A unique difference in how Patients and Providers perceived barriers was found in
how the issue of side-effects was approached in each group. Patients and Providers alike acknowledged that side-effects have been drastically reduced as HIV treatment options have improved, however there remained disconnect between Patients and Providers regarding the perceived impact. Patients felt Providers tended to minimize their concerns regarding the side-effects that they were experiencing. This points to arguments made by Good (1994); Kleinman, Eisenberg, and Good (1978); Roberson (1992) and Young (1978) regarding how issues related to differing perceptions pertaining to illness, disease, and suffering are subjective. Providers in this study viewed current side-effects as being minimal when compared to those of the past and dismissed patient concerns, at times telling patients that “it could be worse”, implying they could be dead. This lack of empathy certainly works against efforts to motivate patients into adhering to treatment. While the side-effects of HIV medications have improved over the last 30 years, not all patients are aware of the many negative side-effects historically associated with HIV medications and that even those who are aware of the past side-effects may still view current side-effects as impacting their quality of life. In either case, pointing to the fact that the patient is alive should not be used as a rebuttal when discussing side-effects —it dismisses the lived experience of the patient and may limit a provider’s ability to instill trust in their provider. Patients do not respond well to shaming.

Trust between a patient and provider has often been highly correlated with treatment adherence regardless of the disease or illness being treated (Altice, Mostashari, and Friedland 2001; Thom and Campbell 1997; Piette et al. 2005;
Blackstock et al. 2012; Kao et al. 1998; Saha et al. 2010; M. Calnan and Rowe 2008; Skirbekk et al. 2011; Fiscella et al. 2004; Hertzberg 1988; Hall et al. 2001; Pearson and Raeke 2000; Thom, Hall, and Pawlson 2004; Jacobs et al. 2006). Studies by Ezzy (2000) Dugdale et al. (1999) and Davies (1997) reported trust as being associated with time spent with patients, however this study suggests that it is not necessarily the length of time sent with a provider, but the time that a provider takes to get to know them (Ezzy 2000; Dugdale, Epstein, and Pantilat 1999; Davies 1997).

Much like the information gleaned during the literature review, for patients in this study trust was not implied, but was built on an initial office visit where they gauged the provider’s experience, compared it to their own and weighed whether or not that provider could relate to them (Gaston 2013; Langebeek et al. 2014; Safran et al. 1998; Street et al. 2008; Henry 2015; Rajaraman and Palmer 2008; R. M. Epstein et al. 2005).

The reported demographic disparities weighed more heavily on the Providers perception. For Patients, the providers’ race, age, or gender were of minimal importance, however same sexual orientation did present as being more important to Patients than Providers. Providers expressed this as a concern by inadvertently referring to themselves as being “straight”. While there was no perceived homophobia, the association of being unable to relate to HIV-positive persons because of one’s sexual orientation comes into question.

Being able to relate to patients tended to take on different meanings between the two groups. Patients initially identified the provider’s experience as
something they used to measure how they were able to relate to one another and therefore establish a sense of trust. Moving forward specific qualities such as age, race, gender, and so on were explored, but resulted in a recognition that Providers tended to place a greater weight on them than Patients did. Again, age was only qualified when it was placed in the context of experience. Patients tended to perceive qualities such as age, race, gender, and sexual orientation of their provider as being inconsequential to the trust they imparted on their provider. Again while the majority of Patient respondents reported a high adherence rate, subsequent interviews failed to identify this as concern. It could be offered that Providers perceive these as bigger barriers because by doing so would deflect personal responsibility for patients non-adherence. I did not find this to be the case, in fact I would say that Providers felt a certain degree of defeat and genuine remorse when a patient who failed to adhere to treatment eventually died.

For providers working in the field of HIV/AIDS the time invested for each patient becomes personal and there is an altruistic approach to care. Hearing the stories shared by Providers regarding patients, an understanding of the weight they bear is better understood. Patient respondents suggested that at times they felt providers came and went too quickly to build a relationship, but Providers offered that at times patients came and went too quickly. Stressing the importance of taking one’s medication becomes frustrating for Providers when the words used fail to be heard. The toll that providers take when trying to reach out to patients might be felt more by case managers who actively follow up on those patients who fail to capture the importance of the message they are trying to send. A Provider who
identified as an MD offered this about the measures a particular case manager takes:

Those who fall out of treatment...they’re not in my job description to reach. Being the primary provider, I frankly leave that to our social workers to try to track them down...but let me just briefly tell you...this woman...her car gets covered with feces, vomit and dirt of various kinds every year because she spends her evenings and nights going out, looking under bridges, scouring the homeless areas, driving around, trying to find people that have fallen out of care... She is the Mother Theresa of Tarrant County.

Throughout the course of this study it became evident that Providers expressed a genuine concern for their patients, and while Provider turnout was not as expected, the responses offered by participating Providers spoke to a devoted interest in improving patient and provider communication and overall adherence rates.

One of the emerging themes that presented in both groups was that of Funding. For patients they felt limited by their income or location—they might not qualify for certain programs. Providers pointed to funding as a barrier because not only was there an insurmountable amount of paperwork involved, in order to justify their funding a certain degree of the patient encounters must be specifically devoted to HIV or AIDS treatment. This approach to treatment offers a myopic response in that the patient experience is built around their HIV status and therefore issues not related to HIV fail to be addressed. While visits tend to be centered on follow-ups to HIV treatment it is important that HIV be not the sole focus, especially when one considers potential barriers to adherence. Providers offered that while they would prefer to take a more holistic approach to patient care, to meet funding requirements discussions related to HIV must be central to
the visit and as such medical issues not specifically related to HIV were often referred out.

This study supports the findings discovered by Kalichman et al. (2007) where they argue the disclosure of ones HIV status to medical providers is difficult for patients. The referral process presents with its own set of problems that were identified in this study. While some of the organizations interviewed were capable of keeping patients within the same system, others reported that referrals were commonplace. Based on participant interviews it became evident that once an HIV-positive patient was referred out they encountered a degree of stigma based on their HIV status. At times this stigma was perceived through body language and the uncomfortable way the preferred provider behaved. Other times it was more overt, with a provider refusing to see a patient at all. For medical professionals to behave in such a manner speaks to an ongoing problem with the stigma that continues to follow an HIV diagnosis. Referrals to providers outside of HIV specific care is undoubtedly going to increase as more HIV-positive persons seek care for more age-related health issues and being able to seek these services should not come with a fear of discrimination. While most Providers interviewed reported that great care is taken in order to screen providers prior to a referring a patient, this continues to be a concern.

The stigma associated with HIV was also reported with certain clinics devoted to providing services for HIV-positive persons. Concerns regarding the inclusion of AIDS in the name of certain service providers was noted as being associated with a level of discomfort in seeking services from those providers. The
perceived stigma associated with the word AIDS was seen as being greater than HIV. Given the notable decrease in AIDS related deaths to use AIDS in an organizations name appears to be antiquated as the majority of those seeking services do not have AIDS, but HIV.

The difference in these words while seeming inconsequential speaks to the perceived value that people place on them. Words used by a provider can hold a great influence on how a patient approaches their treatment. For this study, surveyed Patient’s overwhelming reported that the words used by their providers had positively worked to motivate them to adhere to their treatment; however, during interviews it was discovered there were times when a provider’s word choice was deemed hurtful. While these experiences did not tend to impact the overall treatment adherence of the patients, recalling such experiences, led to an emotional response where at times the interviewees began to tear-up. This response while failing to impact treatment adherence speaks to a sense of agency found throughout this study.

Agency was ultimately defined by a patient’s, for lack of a better phrase, willingness to live. For Patients, failure to take their HIV medicine was associated with suicide. Providers also used this as an explanatory model when attempting to emphasize the importance of adherence. Recall PR03’s anecdote of falling from the top of the Empire State Building, where he emphasized the importance of taking the medicine despite of “feeling well”. Or PR01’s struggle with non-adherent patients “You’re dying. You’re going to kill yourself if you continue this way.”
This study captured the voices from both patients and providers. By filling this gap in the literature efforts to address the role of the patient-provider relationship and the part that communication plays as it pertains to treatment adherence will be better understood.

5.1 Recommendations

This study touched on a number of issues that can be used to better facilitate treatment adherence. Based on this research it is recommended that the Planning Council share these results with providers in their network. An awareness that side-effects, regardless of the fact that they are less severe than those in the past, remains a concern for Patients and the dismissal of these concerns by Providers creates an environment where communication becomes limited.

It was also discovered that perceptions of having an illness or a disease may impact HIV treatment adherence. If patients associate taking medication only when they feel sick, this might prove to be an indicator as to why some patients fail to take their HIV medication as prescribed. It is recommended to the Planning Council that when communicating with less adherent patients taking the time to understand how patients negotiate illness might prove to be beneficial. Additionally, stressing the importance of taking the medication regardless of how one "feels" should continue to be stressed.

Given that HIV has progressed to a health status that is now considered a chronic “disease”, attention regarding the incorporation of the Primary Care Provider in the treatment process might prove to be better model than immediately referring the patient to an HIV specialist. For a patient that has a low viral load and
otherwise not presenting with any complications, by leveraging the strengths of the Primary Care Provider for routine labs and follow ups, this might decrease the burden on HIV-specific clinics. The Primary Care Provider would also be able to address non-HIV specific health concerns, a service that not all HIV clinics can provide due to funding restrictions.

Perhaps one of the more surprising findings that emerged out of this study was the stigma that HIV-positive patients continue to face in the healthcare community. When a patient referred to a provider for unrelated HIV health issues is met with an uncomfortable feeling or a denial of treatment, this creates a barrier in which other health concerns will fail to be addressed. To better counter this potential issue, the Planning Council could have their interns make calls to area doctors in various fields, inquiring about their willingness to treat HIV positive, experience with treating HIV-positive patients, and other related questions. A final list of HIV-friendly providers could be compiled and offered to patients.

Finally, the association regarding words HIV and AIDS are very different. The word AIDS is perceived as being more negative than the word HIV. Further research regarding how organizations use these words in their name should be explored.
CHAPTER 6
REFLECTION

There are certain experiences that cannot be taught. Moving from the classroom and into a real project was an opportunity for me to test myself. In the classroom we can disconnect because the impact is hypothetical. In field research, the impact reached a level I had not expected. To say that I was able to disconnect from the experiences shared throughout this study would be a lie. Being able to disconnect from the survey data was easier because, they were after all just numbers, there was little to get emotionally involved in. As the study progressed into interviews, I found it more difficult to detach and there were situations in which I felt uncomfortable because of the emotions being displayed by the participants. To ask a question that brings tears to someone’s eyes comes with a sense of guilt that is not easily overlooked. Efforts to detach myself were attempted by trying to convince myself that the ability to tease out such emotions was good, because it showed I was asking the right questions—however on a deeper level the guilt remained.

My desire to pursue this study stemmed from past experiences shared with me by friends who are HIV positive as well as those who have died from AIDS. For me the importance of addressing the impact of patient-provider communication on HIV treatment adherence is personal. My hope is that findings from this study can be used to improve adherence and reduce unnecessary deaths.
Perhaps the most disturbing discovery for me throughout this process was the HIV stigma that is still found within the medical community. Entering this study I felt that homophobia would lead the way in regards to stigma, to find that it did not even register was a happy discovery, however it was replaced by a more disturbing one.

Above all as I reflect on my experience as a researcher during the course of this study I am reminded that I am human and the fact that this study impacted me on an emotional level is good—because it is real.
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