

PATIENT AND HEALTHCARE PROVIDER PERCEPTIONS ON LINKAGE TO CARE
AND MEDICATION ADHERENCE AMONG AFRICAN AMERICAN WOMEN LIVING
WITH HIV/AIDS – A QUALITATIVE COMPARATIVE STUDY

By

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To the African American woman living with, yet triumphing over HIV/AIDS . . . whose
inner beauty and strength truly inspire

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TABLE OF CONTENTS

ACKNOWLEDGMENTS.....	4
LIST OF TABLES.....	11
LIST OF FIGURES	12
LIST OF ABBREVIATIONS.....	13
ABSTRACT.....	15
CHAPTER	
1 INTRODUCTION.....	17
Background: HIV/AIDS Health Disparities in the United States (US)	17
HIV/AIDS-related Disparities in the State of Florida.....	20
Antiretroviral Medication Adherence	21
Problem Statement.....	23
Preliminary Study	24
Preliminary Findings.....	27
Emerging Theoretical Concepts	27
Summary of Key Findings	33
Dissertation Research Focus.....	34
2 REVIEW OF LITERATURE	38
Part I - Factors Affecting Medication Adherence among African American women living with HIV/AIDS	38
Perceptions of African American women living with HIV/AIDS.....	39
Review of Key Preliminary Findings	42
Depression and denial	43
Acceptance of HIV status and control of HIV illness.....	46
Self-disclosure of HIV status	47
Finding purpose/relevance.....	49
Provider-patient relationship	51
Substance abuse	53
Peer support	56
Summary of Part I Review.....	59
PART II – Healthcare Provider Perspectives on Medication Adherence	60
Comparative Studies: Providers’ versus Patients’ Perspectives	60
Care Provider Perspectives.....	63
Care Gaps: Current Practice versus the Ideal	64
Summary of Part II Review.....	65
3 METHODS	74

Methodological Approach – Grounded Theory and Thematic Analysis	74
Characteristic Features of Grounded Theory.....	75
Epistemological position: Social Constructionism and Symbolic Interaction	76
Theoretical Perspective.....	76
Grounded Theory: Strengths and Limitations	77
Limitations	77
Strengths	79
Research Strategy.....	79
Study Objectives	79
Eligibility/Inclusion Criteria.....	81
Recruitment and Sampling	81
Data Collection.....	82
Data Analysis	84
Integrity and Protection of Human Subjects	87
Evaluation Criteria	87
Protection of Human Subjects	89
Data sources.....	89
Protection from potential risks	90
Potential benefits to participants	91
Study Significance	91
Researcher’s Reflexivity Note.....	92
4 FINDINGS	99
Demographic Characteristics of Participants	99
Major Categories	99
Category 1: Socio-Economic Context.....	100
Income level, care-giver role and financial responsibility.....	100
Instability.....	101
Education/literacy level	102
Lifestyle	102
Domestic violence/ sexual abuse.....	103
Life-changing traumatic event.....	104
Category 2: Patient Illness Experience	105
Denial	105
Acceptance of HIV status.....	106
Perceived control of HIV disease	106
Self-disclosure of HIV status	107
Motivation	109
Category 3: Mental and Emotional Health	109
Psychiatric disorders.....	110
Depression	110
Emotional distress	110
Instability.....	111
Category 4: Support	112
Social support.....	112
Instrumental support	113

Peer support	114
Category 5: Access to Care	115
Availability of relevant services/ resources.....	115
Affordability of healthcare services.....	115
Accessibility of health care facilities	116
Category 6: Healthcare System.....	117
Complexity of and inefficiencies in the care process	117
Fragmentation of the healthcare system	120
Characteristics of the care setting	120
Resources	121
Category 7: Provider-Patient Interaction.....	122
The provider-patient relationship.....	122
Provider's care approach	122
Provider-patient communication.....	125
Category 8: Patient Characteristics	125
Patient knowledge and understanding	125
Patient disease/ treatment perception.....	126
Patient responsibility/ self-management.....	127
Self-efficacy	128
Developing a Conceptual Model.....	130
Comparative Analysis of Conceptual Models.....	131
Contrasts in Patients' and Providers' Perceptions	131
Socio-economic context.....	131
Patients' HIV illness experience.....	132
Patient characteristics.....	136
Provider-related factors.....	142
Concordance in Patients' and Providers' Perceptions	144
Patient illness experience	144
Patient characteristics.....	146
The healthcare system.....	151
Care-provider related factors	154
Current Practice versus Provider Perceived Patient Needs	162
Summary of Findings.....	169
5 DISCUSSION AND CONCLUSIONS.....	189
Study Objective 1	189
Study Objective 2	190
Study Objective 3	194
Socio-economic Context	195
Patient-related Factors	197
Healthcare System-related Factors	206
Care Provider-related Factors	207
Study Objective 4	211
Conclusions.....	215
Study Limitations	219
Next Steps - Designing Targeted Interventions.....	221

Integration of Conceptual Models	221
Selecting an Intervention Focus: Priority Matrix.....	222
Impact Of Peer Education/Navigation on Linkage to care and Medication Adherence	223
Implementing a Patient Advisory Group	223

APPENDIX

A PATIENT INTERVIEW GUIDE	226
B PROVIDER INTERVIEW GUIDE	228
C PROVIDER DEMOGRAPHIC INFORMATION FORM.....	230
D PROFILE OF CARE PROVIDER PARTICIPANTS	232
LIST OF REFERENCES.....	2388
BIOGRAPHICAL SKETCH.....	2611

LIST OF TABLES

<u>Table</u>	<u>page</u>
1-1 Demographics of participants for the preliminary study	36
1-2 Preliminary study results: patient perceived barriers and facilitators of early linkage and medication adherence	37
2-1 Comparative studies on providers' and patients' perspectives.....	66
2-2 Studies on care provider perceptions	71
2-3 Current practice versus perceived "ideal"	73
3-1 Area 3/13 population profile.....	95
3-2 Refined codes	96
4-1 Summary of provider participants' demographic characteristics	172
4-2 Category 1: Socio-economic context – themes and summary of perceptions ..	173
4-3 Category 2: Patient illness experience - themes and summary of perceptions	174
4-4 Category 3: Mental and emotional health - themes and summary of perceptions.....	176
4-5 Category 4: Support – sub-categories, themes and summary of perceptions ..	177
4-6 Category 5: Access to care – themes and summary of perceptions	178
4-7 Category 6: The healthcare system – themes and summary of perceptions	179
4-8 Category 7: Provider-patient interaction –themes and summary of perceptions.....	180
4-9 Category 8: Patient characteristics – themes and summary of perceptions	182
4-10 Summary of comparative analysis: patient and provider perspectives	184
4-11 Summary of care providers' recommendations.....	186

LIST OF FIGURES

<u>Figure</u>	<u>page</u>
3-1 Map of Area 3/13.....	97
3-2 Sample memo from MaxQDA 11.0.2.....	98
4-1 Conceptual model: Care-provider perceptions of care-seeking & adherence behavior among African American women living with HIV/AIDS.....	187
4-2 Conceptual model: Care-seeking & adherence behavior among African American women living with HIV/AIDS – patient perceptions.....	188
5-1 Integrated model: Care-provider and patient perceptions of care-seeking & adherence behavior among African American women living with HIV/AIDS.....	224
5-2 Priority matrix: Selecting target areas for intervention.....	225

LIST OF ABBREVIATIONS

ADAP	AIDS Drug Assistance Program. This is a grant given to States under the Ryan White HIV/AIDS Treatment Extension Act of 2009, to provide antiretroviral and related prescription drugs to persons living with HIV/AIDS in the low-income bracket who have little or no insurance coverage. http://kff.org/hivaids/fact-sheet/aids-drug-assistance-programs/
AIDS	Acquired Immune Deficiency Syndrome. This is the final stages of HIV infection; at which point, the immune system has become so compromised that the person infected is highly susceptible to opportunistic infections. (http://aids.gov/hiv-aids-basics/hiv-aids-101/what-is-hiv-aids/)
ART	Antiretroviral Therapy. This is the standard treatment in HIV. It is a medication regimen consisting of three or more antiretroviral drugs with the goal of halting the progression of HIV disease by suppressing the HIV virus. (http://www.who.int/hiv/topics/treatment/en/)
CBPR	Community-based Participatory Research. A collaborative approach that facilitates the active involvement of community members in the entire research process from conception to interpretation and dissemination of results; with the goal of improving community health and reduce health disparities.
CHD	County Health Department. Government established and run local public health facilities that function based on the authority and responsibility derived from the state and local governing laws.
DOH	Department of Health. A State established institution charged with the responsibility of protecting, promoting and improving the health of the citizenry through collaborative efforts at the state, county and community levels. (http://www.floridahealth.gov/index.html)
FGD	Focus Group Discussion. Interactive session between a group of individuals who have a common interest(s) or characteristic(s); facilitated by a moderator with the aim of gaining insight into a specific issue. (http://ag.arizona.edu/sfcs/cyfernet/cyfar/focus.htm)
GAAP	Gainesville Area AIDS Project. This is a community based organization that provides resources and services to persons living with HIV in the Gainesville area of Florida.

HAART	Highly Active Antiretroviral Therapy. A “cocktail” of three or more antiretroviral drugs used in combination to effectively treat HIV (also ART). (http://www.cdc.gov/hiv/prevention/research/tap/)
HIV	Human Immunodeficiency Virus. This is a virus that destroys specific cells in the body’s immune system (CD4 or T cells) that normally help in fighting off infections and disease. (http://www.cdc.gov/hiv/basics/whatishiv.html)
HOPWA	Housing Opportunity for Persons living with HIV/AIDS.
HRSA	Health Resources and Services Administration. This is one of the agencies within the US Department of Health and Human Services. Its primary function is the improvement of access to health care services to populations that are uninsured, isolated and/or medically underserved. http://www.hrsa.gov/index.html
IRB	Institutional Review Board. An institute charged with the responsibility of reviewing and monitoring the conduct of research involving human subjects to ensure adequate protection of their welfare and rights. (http://irb.ufl.edu/)
PEP	Positives Empowering Positives. AN HIV support group hosted in the Alachua County Health Department, Florida
PEPFAR	United States President's Emergency Plan for AIDS Relief. This is the US government global initiative to alleviate the suffering and save the lives of those living with HIV/AIDS. http://www.pepfar.gov/about/index.htm
PLWHIV	Person(s) or people living with HIV/AIDS
RYAN White program	This is a federally funded program designed to provide aid to persons living with HIV I order to access services that are not covered under other assistantship programs.

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By

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The introduction of combination antiretroviral therapy has greatly improved health outcomes for persons living with HIV. Despite the reduction in HIV-related morbidity and mortality, African American women continue to be the most disproportionately affected population. In order to effectively address the burden of HIV/AIDS among this at-risk population, there is need to gain a better understanding of the factors that influence and/or affect their care-seeking behavior and specifically adherence to their antiretroviral medications. A preliminary qualitative study was conducted with a sample of the target population. The objective was to determine the patient perceived factors associated with linkage to care and medication adherence. From these, a conceptual model describing the possible interactions personal, interpersonal and structural factors impacting medication adherence was developed. Key findings in the preliminary study were the influence of the patient's illness experience on their care process and the role of the provider-patient interaction in HIV health-related behavior and outcomes.

For this dissertation, the main study objectives were to develop a comparative conceptual model based on care providers' perspectives and determine the differences

and similarities in perceived barriers and facilitators associated with linkage to care and medication adherence in this population. Using the qualitative methodological approach of grounded theory, data was collected from twenty one health care providers – physicians, pharmacists, nurses and case managers – through in-depth interviews. From the data analysis, another conceptual model was generated based on care provider perceptions and narrated experiences. Both models were compared for similarities and differences in perceptions. A key finding was the underlying influence of the socio-economic context of members of the target population. Provider perceptions also revealed sub-groups within the target population with different problems associated with HIV health-related behavior. In addition, provider perceptions on healthcare practices that do not adequately meet the care needs of this population were explored.

This research lays a foundation for the design of targeted interventions to improve linkage to care and enhance medication adherence among African American women living with HIV/AIDS. Various factors are identified at the individual, inter-personal and structural levels; which provide the basis for different intervention strategies.

CHAPTER 1 INTRODUCTION

This chapter provides a background on HIV-related health disparities in the United States, antiretroviral medication adherence, and the premise for the research conducted. A preliminary study investigating perceptions and experiences of African American women living with HIV/AIDS is also described.

Background: HIV/AIDS Health Disparities in the United States (US)

Among all the racial/ethnic groups in the US, African Americans have been faced with the greatest burden of HIV/AIDS since the onset of the epidemic (CDC, 2012a). Presently, there are over 1.1 million people living with HIV/AIDS in the US, and approximately 510,000 of these are African Americans (CDC, 2012a). Compared to other racial/ethnic groups in the US, African Americans have the highest rates of new HIV infections, AIDS diagnosis, and HIV prevalence (CDC, 2012b; Kaiser Foundation, 2013). Although only 12.3% of the US population self-identified as African American in 2010 (US Census, 2010), African Americans accounted for approximately half (48%) of the new AIDS cases diagnosed in 2011 (CDC, 2013). In 2010, the rate of AIDS cases diagnosed (per 100,000) among African American adults and adolescents was 10 times the case rate for Whites. African American men had the highest case rates (75.6) for any group by race/ethnicity and gender, followed by African American women (33.7) (CDC, 2012a). The rate of new cases of HIV diagnosed per 100,000 was 103.6; again the highest for any group. HIV case rate among women was also highest for African American women (38.1) compared to other racial/ethnic groups (CDC, 2012b).

HIV-related mortality rates are also highest among African Americans. In 2009, African Americans accounted for 56% of HIV-related deaths (NCHS). On the average,

survival time following diagnosis of AIDS is lower for African Americans than any other racial/ethnic group (CDC, 2012a). In 2008, HIV was 4th among the leading causes of death for both African American men and African American women between the ages of 25 and 44 years; the highest ranking for any comparative group by race/ethnicity and gender (CDC, 2008). In 2010, approximately 64% of newly diagnosed cases of AIDS among women were African Americans, compared to 15% among Whites and 17% among Latina women (CDC, 2012c). In 2010, African American women accounted for 34% new AIDS cases among African Americans, while White women constituted only 14% of newly diagnosed AIDS cases among whites.

In addition to racial/ethnic disparities, there is also a disproportionate distribution of AIDS diagnoses among African Americans by geographical region. While the District of Columbia has the highest case rate of AIDS among African Americans (per 1000,000), more than half of all African Americans living with AIDS and most of the newly diagnosed AIDS cases among African Americans are in the South (Kaiser, 2011). In 2009, among the 10 states accounting for approximately 71% of African Americans living with AIDS, Florida ranked 2nd (3rd in the US as a whole).

According to the HIV Cost and Services Utilization Study (HCSUS), African Americans are more likely to delay seeking medical care for a number of reasons including access barriers (transportation), limitation imposed by illness severity, and prioritization of other needs over health care (Cunningham et al., 1999; Anderson et al., 2002). Analysis of demographic, clinical and health care service utilization data collected from HIV care sites in different geographical areas of the US between 2000 and 2002 showed that hospitalization rates for persons living with HIV/AIDS (PLWHIV)

were higher for African Americans than for Whites, but no significant differences were found between the two groups for utilization of outpatient services (Fleishman, 2005).

There are also disparities in insurance coverage by race/ethnicity. Based on the HCSUS findings, African Americans living with HIV/AIDS are more likely to have government –funded health insurance or no insurance coverage. Up to 59% of African Americans living with HIV/AIDS were dependent on MEDICAID compared to 32% of their White counterparts. Only 14% of African Americans with HIV/AIDS were privately insured compared to 44% Whites, and 22% had no insurance coverage compared to 17% Whites. Data from 1994-2000 showed that at the time of HIV diagnosis, African Americans were more likely than Whites to be on MEDICAID or have no insurance coverage (Kaiser Foundation, 2011).

It is interesting to note that self-reported HIV testing rates among the non-elderly population (aged 18-64) is two times higher among African Americans than Whites (Kaiser Foundation, 2012). Among those testing positive, 31% of African Americans were likely to be tested in the more advanced stages of HIV disease; similar to Whites (32%) and Latinos (36%) (CDC, 2012c). In a recent release at the XIX International AIDS Conference by the Centers for Disease Control and Prevention (CDC, 2012d), African Americans and younger persons living with HIV/AIDS (PLWHIV) were “least likely to receive ongoing care and effective treatment”(CDC, 2012d). Analysis of data from the CDC surveillance systems found that 34% of African Americans living with HIV are receiving continuous care compared to 38% and 37% of Whites and Latinos respectively. Also, viral suppression has been achieved in only 21% of African Americans living with HIV compared to 30% among Whites and 26% among Latinos.

HIV/AIDS-related Disparities in the State of Florida

Florida accounts for 11.7% of all persons living with HIV/AIDS; which was estimated to be approximately 135,000 in 2010 (Florida DOH, 2010 annual report). In the same year, Florida ranked 3rd in the US with respect to the prevalence of HIV infection. In 2010, HIV was the 6th leading cause of death in Florida. Among African Americans, it was the 4th leading cause of death, down from number one for the first time since 1988. Among African American women, it was the 2nd leading cause of death, also down from the top for the first time in 22 consecutive years (Florida DOH, 2011).

In Florida, African Americans constitute only 14% of the adult population, but account for 44% of HIV cases in the adult population. Both African American men and African American women are disproportionately affected by HIV/AIDS. Newly reported HIV cases in the adult population for the year 2012 was five times higher among African Americans men compared to White men (Florida HIV/AIDS Annual Report, 2012). The case rate among African American women was also higher (14.8 times) compared to White women (Florida HIV/AIDS Annual Report, 2012). In the adult population (as at 2011), for every 40 African American men, one was living with HIV compared to one out of every 195 among White men. For women, it was one in every 60 African American women and one in every 1,085 White women (Florida DOH, 2012). It is estimated that approximately one in 30 African American women will be diagnosed with HIV at some point in the course of their lifetimes (Florida DOH, 2012a). Among women, HIV-related deaths and HIV death rates are highest for African American women and was the fifth leading cause of death for African American women aged 25 – 44 in 2012 (Florida DOHa).

There is also evidence of disparities in HIV-related morbidity and mortality. Analysis of data spanning from 2007- 2012 found that median survival time - from the time of diagnosis to AIDS to time of death – was 60 months for African Americans. This was significantly higher among Whites (83 months) though similar for the Hispanic population (Florida DOH, 2013). Among African Americans, median survival time was also lower for women (57 months) compared to 63 months for men (Florida DOH, 2013).

Antiretroviral Medication Adherence

The term ‘medication adherence’ in HIV/AIDS care refers to the ability of a person living with HIV/AIDS to manage and maintain a therapeutic regimen (typically HAART - highly active antiretroviral therapies) prescribed for the suppression of the HIV viral replication in order to enhance immune function (APHA, 2004). The use of HAART has proven to be highly successful in controlling viral replication. As a result, the disease progression is slowed and persons living with HIV are able to live longer with improved quality of life. However, the efficacy of treatment has been shown to have direct correlation with the patient’s level of adherence to the prescribed regimen (Low-Beer et al., 2000; Nachega et al., 2007; Shuter et al., 2007; Martin et al., 2008; Ford et al., 2010). Medication adherence therefore, is a key determinant of therapeutic success in HIV treatment. In contrast, non-adherence to antiretroviral therapy (ART) has both clinical and economic implications (Munakata et al., 2006). Non-adherence to antiretroviral treatment is typically associated with increased HIV-related morbidity and mortality, and increase in health care expenditure and resource utilization from a health system perspective.

There has been considerable research done in the area of antiretroviral medication adherence. A myriad of factors have been associated with non-adherence to antiretroviral therapy. Barriers and/or facilitators of medication adherence among PLWHIVs have been categorized into factors related to the patient, the treatment/regimen, the patient-provider relationship, and the environmental factors (including the social environment, economic status, structural environment, and the health care system). (Ramirez & Cote, 2003; Konkle-Parker et al., 2008; Vervoort et al., 2007; WHO, 2003; Ickovics and Meade, 2002)

Patient related factors include health beliefs (the patient's beliefs and perceptions about the illness and/or the medications they are taking and their ability to adhere to the treatment regimen (i.e. their- self efficacy); literacy level, educational level, substance abuse, knowledge of treatment, stress, anxiety and depression. More recently, patients' 'readiness' to start treatment has been identified as a strong determinant of adherence and has since been included in the guidelines for initiation of antiretroviral therapy (Grimes & Grimes, 2010).

With regards to the medication, factors that have been identified include the type of medication (formulation and pill size), the side effects experienced, number of pills, frequency of dosage, and generally the complexity of the medication regimen (Puigventós et al., 2002).

The provider-patient relationship has also been cited as influencing patient adherence (Murphy et al., 2003; Ramirez & Cote, 2003). This encompasses patient's perception of how comfortable they feel in interacting with the health care professional, patient's perception of the provider as being competent, patient's ability to seek

information by asking questions, how clearly and effectively the provider communicates information to the patient and individual characteristics of the health professional (experience with antiretroviral therapy and treatment preferences), and accessibility of the provider. Literature also suggests that trust in the health care provider influences medication adherence in HIV treatment (Altice L, Mostashari & Friedland, 2001; Whetten et al., 2006; Konkle-Parker et al., 2008). Factors related to the environment include perceived social support, perceived stigma, access to care, and availability of resources like transportation and finances (Russel et al., 2003; Konkle-Parker et al., 2008).

Problem Statement

It is evident that African American women in Florida are disproportionately affected by HIV/AIDS. For 22 consecutive years (until 2010), HIV/AIDS remained the leading cause of death among African American women aged 25-44 years in Florida (Florida Department of Health, 2012). African American women also have higher HIV incidence and mortality rates, and are the least likely to adhere to medication use of all sub-populations in Florida. They accounted for 69% of all adult women infected with HIV by 2012, but constitute only 16% of the female population in the state (Florida Department of Health, 2012). The interplay of many factors has been identified as reasons for higher impact of HIV in the African American population nationally. For example, the recent US national HIV/AIDS strategy identified sexual transmission (often within the environment of already high HIV and STDs prevalence), injection drug use, poverty, stigma, homelessness and lack of access to healthcare as factors which may affect this population (NHAS, 2010).

The use of highly active antiretroviral therapies (HAART) has proven to be highly successful in controlling viral replication; and thus slowing disease progression as well as improving quality of life. However, the efficacy of treatment is directly correlated with the patient's level of adherence to the prescribed regimen (Low-Beer et al., 2000; Nachega et al., 2007; Shuter et al., 2007; Martin et al., 2008; Ford et al., 2010). To reduce morbidity and mortality in the target population, it is therefore necessary to investigate the barriers to and facilitators of HIV medication adherence. In addition, it is important to understand how these barriers and facilitators influence adherence behavior to produce specific health outcomes.

Preliminary Study

To gain some insight into the factors influencing medication adherence, a pilot qualitative study was conducted to explore the perspectives and experiences of African American women living with HIV/AIDS relative to antiretroviral treatment (ART). The objective of the qualitative study was to derive a conceptual model that would effectively describe medication use and adherence behavior of African American women living with HIV/AIDS by investigating perceived barriers and facilitators/ motivators associated with medication adherence behavior in this population using *Grounded Theory* as the methodological approach (Glaser & Strauss, 1967; Charmaz, 2006).

A community based participatory approach (CBPR) was adopted for this study. An advisory board was constituted to guide the research. Members of the advisory board were drawn from the County Health Department, a community-based organization, University of Florida and an HIV support group. The five members of the board included the minority AIDS program coordinator, faculty from the University of

Florida, an active member an HIV support group, an HIV clinical staff, and an HIV advocate/volunteer engaged in HIV awareness activities in the community.

The advisory board helped generate the research objectives and interview questions based on their expert knowledge of and interaction with the target population. They met periodically to review progress and give recommendations on further actions. Members of the board provided valuable insight about the target population and helped develop the protocol and interview guide for the study. At the end of the study, findings were reviewed and endorsed by the board.

To be included in the study, participants had to be African American, female, 18 years and above, be able to speak English, been diagnosed as HIV positive and currently on an antiretroviral regimen. Participants were drawn from HIV/AIDS support groups in the local community. IRB approval for this study was obtained from the University of Florida. Fliers advertising the study were distributed and interested participants were requested to call or email the principal investigator. Those who met the inclusion criteria and consented to participating in the study had an interview scheduled at a time and venue of their convenience with due consideration to privacy and confidentiality.

In keeping with the iterative process of grounded theory which involves the simultaneous collection and analysis of data, categories emerging from the preliminary data analysis of the initial interviews informed the further selection of participants (Bowers, 1989; Richards & Morse, 2007). Theoretical sampling involving the search for relevant data with the aim of elaborating and refining the emerging categories,

continued until no new properties of these categories emerged (saturation). Saturation was reached after interviews with ten participants.

The interviews were in-depth using a semi-structured interview guide (Appendix A). Interviews were scheduled separately for each participant. All the interviews were audio-recorded with written consent from participants. All interviews were done by the principal investigator. Demographic information was collected and open-ended questions used during the interviews (Appendix A). Based on emerging categories, other questions evolved as the interviews progressed. The length of the interviews varied; ranging from 27 to 72 minutes. All participants were compensated with a \$20 gift card for their time and travel.

The interviews were transcribed verbatim. An initial line-by-line open coding was used to categorize and summarize the data (Glaser, 1978), followed by more focused coding centered on the significant codes and categories that tended to be more conceptual. Memo-writing (the construction of analytical notes) was on-going throughout the coding process. This facilitated constant comparative analysis, aimed at comparing data to data (including that from relevant literature), and data to codes and categories in order to identify similarities and differences. This also aided the abstraction of relevant theoretical categories and revealed gaps that needed further investigation. All these led up to the theoretical level of coding where relationships between categories emerging from the data were constructed (Charmaz, 2006). A conceptual model was then developed describing the process of becoming adherent to antiretroviral medication among Black women living with HIV/AIDS from their perspective (Figure 4-2).

Preliminary Findings

The demographic characteristics of the participants are summarized in Table 1-1. All the participants were native-born African American. Participants asked to list their antiretroviral medications and describe the regimen and all reported having knowledge of their current medications. However, medical records were not verified to confirm accuracy of medication knowledge. Most participants (8) reported optimum adherence with only two participants admitting to having occasional missed doses.

Perceived barriers and facilitators to medication adherence: Initial coding of the data identified the perceived barriers and facilitators. These are categorized into intra-personal, inter-personal, medication-related and healthcare system-related factors (Table 1-2).

Further data analysis was aimed at gaining understanding about the mechanisms by which the factors identified actually influence care seeking and medication adherence behavior in this population. Findings suggest that these are influenced directly by healthcare process/system factors (including the healthcare provider) and indirectly, but significantly by factors associated with their illness experience (Figure 1-1).

Emerging Theoretical Concepts

Four theoretical concepts emerged from the data analyses.

Emerging Theoretical Concept 1: Linkage to care is associated with the nature of the referral; with early linkage being more likely if referral is active versus passive.

Early linkage to care was associated with initiating the following active referral steps at the point of HIV diagnosis: the patient was adequately counseled; clinical appointment was fixed; and adequate social support was provided, for example -

transportation arrangement, case management referrals, reminder(s) about appointments through telephone calls, and provision of escorts for appointments.

Participant: When I got the news they immediately made the appointment for me because . . . see at that time I was living out in (*names a County*) . . . and they made doctor's appointment for me so I could immediately be put on the meds . . . for doctors and everybody to get me immediately in, get me checked out, get set up with doctor's appointment, get me on the medications – they gave me some motivation to want to live. Cos I didn't know the seriousness of it until I was told the seriousness." [*Linked to care immediately after diagnosis*]

Persons who were not counseled, and/or simply told verbally to see a doctor or given written information to make an appointment at the local health department (passive referral) were unlikely to follow through with linkage resulting in considerable delay (often months or even years) before entry into care.

Emerging Theoretical Concept 2: The HIV illness experience of African American women living with HIV significantly influences their HIV health-related behavior (care-seeking, medication adherence, retention in treatment).

Illness experience refers to the patient's perception of the disease (HIV) and the meaning ascribed to their experience of having the disease. Participants typically reported an initial state of denial and a common experience of depression. This point for some was also characterized by substance abuse (illicit drugs, tobacco, and/or alcohol). In this phase medication adherence was poor.

Participant: In that 6 months period of time I was just blank. I was trying to numb everything out. I wasn't trying to think about the disease at the time. I was just trying to get it out of my mind. With that I did drugs to keep it out . . . yeah, to wash it away. [*Referring to substance abuse*]

Critical points associated with change in adherence behavior included

1. Acceptance of HIV status;

2. Perception of having control over HIV disease;
3. Self-disclosure of HIV status to significant persons (especially family members); and
4. Finding a reason/purpose for living (Figure 1-1).

Change in perception of HIV disease and treatment was identified as mediating the transition from denial to acceptance of HIV status. This was partly attributed to an increase in HIV knowledge and also associated with interaction with other persons living with HIV (PLWHIV) perceived as living “normal” lives. On acceptance of status, entry into care and/or ART adherence was more likely.

Participant: And I saw all these people that were living with this virus and they were happy, they were OK with themselves. I wanted what they had . . . They were living productive lives and they were making a difference. . . I wanted to be like them so someday I could live with this virus and be OK with me. And I had never thought that you could. And then I saw (mentions name) . . . it's like ‘wow’, I could do this. I could be OK with me and I don't have to be ashamed . . . [*On coming to terms with having HIV*]

In addition to explicit detailing on the importance of medication adherence and the consequences otherwise, participants reported being ‘empowered’ by the ‘success’ they perceived others to have in managing their lives despite living with HIV. Gaining control over the disease was instrumental to becoming pro-active in HIV self-management (asking questions, seeking clarifications from care providers, etc.)

Participant: I studied more about the virus, I learnt about it. Not only that I had it, but about it to know it and understand the things that I needed to do so that I can keep it under control. How I could take control of it. I didn't have to allow it to dictate my life. And when I learnt how to do that, I was ok with me. [*Following interaction with other PLWHIV*]

Positive response from family members on disclosure of status provided them the motivation to live, while affiliation with ‘peers’ provided the needed social support to engage in behaviors that promote healthy living including medication adherence. For

some, self-disclosure served to 'deflect' stigma and empower them as it meant medications could be taken without the need for discretion.

Participant: And I began not to let to people dictate to me. And I don't care what you got to say about the virus cos I tell you myself. You ain't got to tell anyone. I'm telling people myself. So that took the sting of knowing that [I] had HIV away. I'll tell you first. You ain't got nothing to tell anyone. So in that perspective, that made it better for me. I put it out. I rather put it out there than somebody else. So I took the initiative to take my life back so I can live my life. So the shame went away. [*Participant - deflecting stigma*]

There were three recurring themes associated with finding reason to live – caregiver role; HIV advocacy; and renewed faith in God. The majority had children, so fulfilling their caregiver role was a strong motivation to live. Involvement in HIV advocacy activities through membership in HIV support groups reportedly gave a sense of relevance. Generally, there was a common belief that God was all sovereign and had sustained their lives for a purpose. The resulting motivation to live, reportedly increased self-efficacy to make the needed lifestyle changes including quitting substance abuse and becoming more adherent to taking their medication.

Participant: And I began to be more into the community and people knew me. And they call and they ask for me specifically to come to their places and to speak to them . . . I began to understand that I was really needed in more ways than one. And I really had a purpose . . . I needed to make sure I stay healthy in order to be useful, because then my meds . . . I made sure I took them on time . . . the way I thought about the virus was totally different . . . [*On how HIV advocacy gave her a sense of purpose*]

Emerging Theoretical Concept 3: The position on the 'trajectory' of HIV illness experience influences medication adherence behavior; with points further along the trajectory (perceived control, self-disclosure and finding purpose) associated with better medication adherence.

Persons who perceived themselves to have acquired some measure of control over their lives and HIV disease, those who had disclosed their HIV status to others, and/or those who believed that they had reason to live were more likely to take their antiretroviral medications and stay in care.

Participant: I wasn't asking questions before. I really started asking the questions and I would take the initiative to write them down before I went so I wouldn't forget what I wanted to ask, and I was inquisitive about why made my body does this . . . I wanted to know why. I began to take the initiative to take my own care seriously and to take control of it, so I could live.
[Participant about self-management following perceived control of illness]

Emerging Theoretical Concept 4: Key factors that facilitate medication adherence at strategic points along this illness trajectory include the patient-provider interaction; and interaction with other PLWHIV (Observational learning)

Participants characterized a good provider relationship as one where the provider was caring; knew them as a person; and was committed to their wellbeing. The care approach that served as a wake-up call for some was described in terms that may be interpreted as paternalistic with the physician issuing a stern warning regarding the outcome of continued non-adherence. However, given the context of an established provider-patient relationship, it was perceived much like a "tough love" approach. In one participant's words:

Participant: She asked me if I wanted to die, basically. She sat me down one day and . . . cos I wasn't being adherent (*crying*) I was taking my meds sometimes, and sometimes I wasn't taking them. She was the very first person that was straight up with me about the importance of me taking my drugs and what I was truly doing to myself by playing with the meds . . . The way she asked me did I wanna live or did I wanna die . . . She put it point blank.

Other elements of the care approach that enhanced adherence behavior were being open about treatment progress, focusing on other needs (emotional, psycho-

social), affirmation as “normal” people, and respect. A common theme resonating through the narratives was the impact of interacting with other PLWHIV perceived as living relatively healthy and productive lives. This reportedly helped to change their perception of HIV disease and treatment, providing motivation and self-efficacy to be adherent.

Participant: She [PLWHIV] shared her experience with me and that’s when I began to open up and feel like you know, that I didn’t have to close up and that there was more. Then I started to say, ‘well if she can do it, then I can do it.’ I can be more involved in what was going on and I didn’t have to be silent about it.

The theoretical model developed was based on the emerging theoretical concepts from our study (Table 1-2), and describes the care-seeking and medication adherence behavior for African American women living with HIV/AIDS. Findings from other studies demonstrate that referral to care is critical to early linkage in HIV care. Passive referrals were found to be less effective, compared to an active referral whereby a firm appointment is scheduled and needed support is provided (Garland et al., 2011; Hightow-Weidman et al., 2011; Giordano et al., 2005; Mugavero et al., 2007).

Our findings in this study sample also suggest that knowledge about HIV disease and efficacy of ART is low at the time of diagnosis and treatment initiation. Change in perceptions about the disease and/or ART is critical to acceptance of HIV status and perceived control of disease. Knowledge about HIV treatment has been associated with better medication adherence (Weiss et al., 2003). The challenge in this population however, is to determine when patients are receptive to the relevant information given their ongoing illness experience. Patient counseling has to be timely and tailored to meet patient-specific needs.

The philosophy of the African American women interviewed for this study is that treatment should be holistic – encompassing the whole individual – body, spirit and mind (Landrine & Klonoff, 1992). Our findings demonstrate that the care expectations and the dynamics of the provider-patient relationship is perceived differently from the “professional” medical model that is disease-oriented. The care expectations of this study sample are that the health care provider [1.] focuses on her as a whole being that needs medical, emotional and spiritual healing and not exclusively on the disease and the physical symptomatology (Bailey, 1987); [2.] shows interest in her as a person; [3.] shows her respect as a deserving individual; and [4.] is caring, empathic and sensitive to her concerns. Care providers need to understand the care needs of this population and adopt a patient-centered approach.

Observing other PLWHIV was reported to have a dramatic effect on adherence behavior. Findings from other studies demonstrate that integration of peer workers or peer navigators (i.e. persons who are living with HIV) in the HIV care team enhances medication adherence (Marino, Simoni & Silverstein, 2007 Dutcher et al., 2011; PEER Center, 2012a). Peer workers are typically trained and are themselves adherent to their ART (PEER Center, 2012b). As part of the care team, they facilitate early linkage to care by helping the newly diagnosed patient navigate the healthcare system. They are also there to give emotional, informational, and appraisal support, and provide mentorship for achieving treatment adherence goals.

Summary of Key Findings

The conceptual model shows that the HIV illness experience of the African American woman is at the core of her HIV health-related behavior. Her illness experience is shown to significantly affect her response to HIV diagnosis, her decision

to seek clinical care and adherence to treatment. The model describes the relationship between the illness experience and the clinical care process, and also identifies possible mechanisms through which the provider-patient interaction and observational learning affects medication adherence. Enhancing medication adherence requires that health care providers be more patient-centered and holistic in their care approach. Integration of peer navigators into the HIV care team should also be considered as a strategy effective in facilitating early linkage and enhancing medication adherence.

From a health system perspective, the HIV care process appears to be a linear process with the objective of getting newly diagnosed patient linked to care, evaluated for treatment, initiated and maintained on ART. However, our findings suggest that while care providers may be focused on HIV disease management, African American women living with HIV are focused on their HIV illness experience and concerned about the meaning(s) it brings to their lives. Movement along the 'trajectory' of this illness experience is pivotal to health-related behavior including medication adherence.

Dissertation Research Focus

From the preliminary findings, the health care provider was perceived as playing a significant role in facilitating medication adherence in the target population. The next phase of the study therefore focused on deriving a comparative conceptual model based on health care provider perceptions and experiences on factors that influence linkage to care and medication adherence among African American women living with HIV/AIDS. The purpose of the study was to determine the concordance between patient perceptions and provider perceptions on factors that determine early linkage to HIV care and influence medication adherence in this population.

Research findings also suggest that there are disparities between healthcare provider perceptions of what needs to be done to enhance patients' medication adherence and what actually happens in practice (Reif et al., 2006; Park-Wyllie, Kam and Bayoumi, 2009). This dissertation also assessed health care provider perceptions of clients' medication adherence needs and current health care practices that are barriers to adherence behavior in the target population. For this study, health care providers referred to physicians, pharmacists, nurses and case managers. In this dissertation, the terms 'care provider' and 'provider' are used interchangeably with healthcare provider.

The immediate objectives of the study were -

1. To derive a comparative model of medication adherence behavior of African American women living with HIV/AIDS based on health care provider perceptions and experiences.
2. To compare patient perceptions and health care provider perceptions of factors that help to facilitate early linkage of African American women newly diagnosed with HIV to care.
3. To compare patient perceptions and health care provider perceptions of factors that influence medication adherence behavior of African American women living with HIV/AIDS.
4. To explore differences between health care provider perceptions of medication adherence needs of African American women living with HIV/AIDS and current HIV care practices.

Table 1-1. Demographics of participants for the preliminary study

Demographic characteristics	Number (%)
Race/Ethnicity	
Native born African American	10 (100)
Age category	
35 – 39 years	1 (10)
≥ 40 years	9 (90)
Marital Status	
Single	3 (30)
Married	3 (30)
Separated	1 (10)
Divorced	3 (30)
No. of children	
Have no children	1 (10)
Have children	9 (90)
Maximum = 6	
Minimum = 1	
Educational attainment	
High school	8 (80)
Some College credit	2 (20)
Employment status	
Unemployed	10 (100)
No. of years since HIV diagnosis	
Mean = 13.4	
Range = 3 - 24	
Knowledge of current medications (self-reported)	
Yes	10 (100)

Table 1-2. Preliminary Study Results: Patient Perceived Barriers and Facilitators of Early Linkage and Medication Adherence

Intra-personal (patient-related factors)

- HIV knowledge
- Beliefs and perceptions of HIV disease and treatment
- Denial/ Acceptance of HIV status
- Mental/emotional wellbeing
 - Depression
 - Suicide ideation
 - Substance abuse [alcohol, tobacco, illicit drugs]
 - Stigma [perceived and internalized] – emotional distress, fear
- Perceived control of HIV disease
- Self-disclosure of HIV status
- Inherent distrust in the health care system
- Sense of relevance/purpose
- Patient involvement in care interaction

Medication-related experiences (patient-related factors)

- Side effects
- Large pill size [difficulty in swallowing]
- Complexity of regimen [Multiple drugs, co-morbidities]
- Chronic treatment [Overwhelming, challenging]
- Treatment outcomes [Perceived efficacy, clinical markers]
- Dosing reminders

Inter-personal factors

- Provider-related
 - Provider-patient relationship [Caring, trust, open]
 - Provider care approach [Holistic, patient-centered, respectful vs. judgmental, insensitive, discriminatory]
- Support
 - Social support [love and acceptance from family]
 - Peer support [Modeling, support group]

Health care system related

- Consistent care-provider
- Active versus passive referral (specific to linkage to care)
- Availability of patient counseling/ education

CHAPTER 2 REVIEW OF LITERATURE

In this chapter literature relevant to the research area is reviewed. The review is in two parts. The first part is a review of research investigating factors relevant to and/or associated with medication adherence in African American women based on the preliminary findings. The studies that do not focus exclusively on African American women had samples with a disproportionately high proportion of the target population. The second part focuses on studies comparing provider and patient perceptions of barriers to medication adherence; studies on health care provider perceptions on factors influencing antiretroviral medication adherence; and those assessing care gaps between current HIV care-related practices and 'the ideal' (what providers think would work better to enhance medication adherence in the target population).

Part I - Factors Affecting Medication Adherence among African American women living with HIV/AIDS

Antiretroviral adherence has been shown to have strong correlation with HIV viral suppression, and is associated with decrease in rates of development of drug-resistant HIV strains, decrease in mortality rate, and improvement in patients' quality of life (WHO, 2003; Chesney, 2006). To achieve HIV viral suppression which is the therapeutic goal of antiretroviral treatment, medication adherence rates of 95% and above are considered necessary (APHA, 2004; APhA 2009). Findings from various studies in different patient populations with HIV and using different methods of adherence measures clearly demonstrate that medication adherence rates in patients with HIV disease are below this target (McNabb et al., 2001; Arnsten et al., 2001; Mannheimer et al., 2002; Paterson et al., 2002; Bangsberg et al., 2002; Wagner et al., 2003; Howard et al., 2002).

Compared to other racial/ethnic groups, African Americans living with HIV have been found to have lower rates of adherence to their prescribed antiretroviral regimen. (Schackman et al., 2009; Giordano et al., 2010). African American women particularly report significantly lower adherence to ART compared to other populations and as a consequence have high mortality rates (Hodder et al., 2012; Murphy et al., 2012)

Perceptions of African American women living with HIV/AIDS

A review of literature on adherence behavior in antiretroviral therapy found a limited number of studies that specifically explored the perceptions of African American women living with HIV with regard to barriers to and/or facilitators of antiretroviral medication adherence. In a qualitative study by Edwards (2006), the purpose of the study was to explore the association between perceived social support and ART adherence. Data was collected using journals and semi-structured interviews. Participants were all African American women living with HIV (n=20). Specific social issues identified by the participants as constituting barriers to HIV medication were “HIV/AIDS-related stigma, feeling unloved and uncared for, relationship turbulence, and being married to an HIV-positive partner” (Edwards, 2006). Participants also identified factors that facilitated medication adherence and these included having a supportive family and the presence of young children in the lives of these women.

Another study that had 36 HIV positive women participants of diverse racial/ethnic background focused on understanding the patterns, barriers and facilitators to medication adherence in women caring for children (Wood, Tobias and McCree, 2004). Few of the women reported continuous adherence or non-adherence since initiation on antiretroviral therapy. Most reported shifting patterns of adherence over their medication use history. Along with previously established difficulties, the women’s

discussions about barriers and facilitators of adherence tended to center around their relationships with adult family members. The nature and quality of these relationships (supportive or conflicting) were identified as key factors affecting adherence. Parenting was generally reported as being significantly stressful, but they clearly cited their relationships with the children as giving them a sense of purpose and serving as powerful motivation to keep up with care.

In a comparison of women living with HIV/AIDS in the pre-HAART era and the HAART era, Schrimshaw, Siegel and Lekas (2005) examined potential ethnic/racial differences within each time period, and changes between the two time periods. The investigators identified three major categories of attitudes towards antiretroviral medications – negative attitudes towards antiretroviral medications; perceived benefits/effectiveness of antiretroviral medications; and attitudes towards side effects. HAART era women had less negative attitudes toward antiretroviral medications, better perception of benefits and were more accepting of side effects. With respect to racial/ethnic differences, within both time periods, White women reported the most favorable attitudes and African American women reported the least favorable attitudes. The authors suggested that the prevalence of negative attitudes towards antiretroviral medication among African American women may account for the disparities evident in health outcomes in this population.

In another study, the investigators targeted the African American low-income population in the South West of the US (Konkle-Parker, Erlen and Dubbert, 2008). The objective of the study was to identify barriers and facilitators associated with medication adherence with long term objective of deriving data to inform the design of an

adherence intervention in this population. Twenty participants were recruited for focus groups and content analysis employed to identify major emerging themes. Barriers cited by participants included “the perceived burden of extra planning, denial, life stress, difficult characteristics of the medicines, social stigma and shame”. Enabling factors identified included “acceptance of the diagnosis, thinking about the consequences of not taking the medicines, prayer and spirituality, improvements in the medicines, and support from family and friends”.

In a study of HIV-positive African-American women on HAART (Sankar et al., 2000), the investigators sought to understand the concerns and perceptions that promote or deter adherence to antiretroviral medication by HIV-positive African-American women” by exploring their beliefs and practices. They used discourse analysis to identify patterns and variables associated with adherence practice from the narratives of the participants (n=15); and sources of influence that served to motivate or undermine adherence. Participants were asked to rate themselves with respect to adherence and meeting up with clinic appointments. Their attending physicians were also asked to assess the participants on the same measures. Findings showed that fear of stigma constituted a major barrier to medication adherence. The authors’ reported that stigma may be internalized as well as perceived. They stated that the fear of stigma was a reflection of the non-adherent participants’ “desire to remain unmarked to themselves as well as to others to avoid the implied moral judgment associated with a stigmatized condition”. Non-adherence to their medication was associated with stigma and what could be interpreted as an avoidance coping mechanism drawing from the authors’ report that those categorized as “*mostly adherent*” and “*somewhat adherent*”

made reference to their missed doses in the context of not wanting to be reminded that they had the disease. Persons in these categories also tended to not identify with having HIV (i.e. being more or less in denial) and took on a passive role in their care as characterized by putting the responsibility of ensuring adherence on the health care providers or God. Conversely, participants categorized as “*always adherent*” made no reference to stigma but rather conveyed in their narrative an acceptance of their HIV status. Adherent participants also made more reference to the physician’s directives and scientific rationale; demonstrating, according to the authors, substantial knowledge and understanding of the mechanism of both the disease and the antiretroviral treatment. Non-adherent participants reported being conflicted by multiple sources of social authority including the media, God, and family that were not always in resonance with professional authority (the physicians).

Summary: It is evident that perceived barriers and facilitators associated with antiretroviral adherence in African American women living with HIV are centered around their beliefs and attitudes as related to HIV disease and treatment; HIV illness and treatment-related experiences; and interpersonal relationships with specific others like family members and health care providers.

Review of Key Preliminary Findings

Relevant literature was reviewed to determine other research findings on the more significant factors identified from the preliminary study which focused on patients’ perspectives. Factors reviewed include – depression and denial, substance abuse, peer support, acceptance of HIV status and control of HIV illness, self-disclosure of HIV status, finding purpose/relevance, HIV advocacy, and the provider-patient relationship.

Depression and denial

Depressive symptoms are more commonly experienced by persons living with HIV than in the general population (Ahdieh-Grant et al., 2005). Depression has been associated with poor adherence to ART (Kacanek et al., 2010; Kishoff, Campbell and Naidoo, 2012). Consistently, among those living with HIV, women have reported higher rates of depressive symptoms than men (Hudson et al., 2001; Cook et al., 2002; Wisniewski et al., 2005; Moneyham et al., 2005). Research findings also demonstrate that among African Americans living with HIV, women are more susceptible to emotional distress and depressive symptoms; and report coping with HIV to be more challenging than men (Linn, Poku, Cain, Holzapfel, and Crawford, 1995; Fiest-Price and Wright, 2003).

In a study focusing on depressive symptoms among African American women living with HIV (Moneyham, et al., 2000), secondary data analysis was used to examine and describe the level of depressive symptoms in this population. A sub-sample of 152 African American women was identified from a larger cohort of women. The objective of the study was to determine the significant correlates of depression which included “self-esteem, family cohesion HIV symptoms and quality of life” (Moneyham et al., 2000). Findings from this study also determined that the mean score for depressive symptoms in this sub-sample was much higher than previously determined in other samples of African American women and men respectively.

In another study by Moneyham et al. (2005), in which most of the participants (84%) were African American women, depression scores for 93% of the participants were between 16 and 56, with a mean of 24.05 and standard deviation of 12.72. The objectives of the study were to identify variables that had potential to be used as

indicators of risk of depression; and assess the mediating effects of coping and social support. The investigators hypothesized that social support and coping were mediators of the association between HIV-related stressors and depression. Their findings determined that denial as a coping strategy was one of the variables significantly correlated with depression. Other coping strategies that were identified included social support, withdrawal, and engagement in spiritual activities. The correlation of denial with depressive symptoms in this population was positive with the most depressed women resorting to denial and withdrawal/isolation as coping strategies.

In a study by Catz et al.(2002), the objective was to evaluate the psychological distress experienced by low-income women living with HIV/AIDS who were from minority groups in association with their self-reported coping mechanisms. Of the sample recruited, most (84%) were African American. The researchers also stated that they “sought to understand how the women’s health status, demographic background and psychosocial factors contributed to their distress” (Catz, Gore-Felton and McClure, 2002). Measures of depression, anxiety, perceived social support and coping were obtained as well as information such as time since HIV diagnosis, CD4 count and demographic characteristics. For this study, specific sub-scales of the Ways of Coping Questionnaire (WOC) were evaluated – *Planful Problem Solving* and *Escape-Avoidance*. Greater degrees of escape avoidance were found to be associated with less social support and less planful problem solving. Experience of more life stressors was contributory to higher levels of depression. Participants in the study were also more likely to use avoidance coping mechanisms to deal with their distress. Escape avoidance is an emotional coping mechanism where the intent is to take one’s focus off

the stressor and literally “escape” into wishful thinking to the exclusion of the stressor (Skinner et al., 2003). This is a passive coping mechanism similar to denial. Common media of escape include the use of alcohol and other addictive substances.

In a prospective cohort study investigating the effects of depression and mental health-related quality of life on the use of HAART among women living with HIV, Cook et al. (2002) found that high levels of depression and poor mental health were prevalent in the cohort and significantly associated with HAART non-adherence. Using random effects regression models, the longitudinal effects of depression and mental health on probability of using HAART were estimated while controlling for multiple clinical indicators, demographic characteristics, behavioral factors (illicit drug/alcohol use, participation in clinical trials), health care service utilization features and study site. Those receiving treatment for mental health were more likely to adhere to HAART compared to those who were not being treated for depression and/or other mental health problems.

Being in denial of one’s HIV status has been associated with internalized stigma, anxiety, depression and use of alternative medicines, which are all known barriers to antiretroviral adherence (Weiss et al., 2011; Vervoot et al., 2007; Nam et al., 2008; Konkle-Parker et al., 2008). Denial is a common passive coping strategy that is employed by individuals following diagnosis of their HIV and this is not different among African American women (Fiest-Price and Wright, 2004). Denial following HIV diagnosis among African American women living with HIV is believed to be associated with attitudes and beliefs about HIV prior to diagnosis. African American women have been reported as under-estimating their susceptibility to HIV infection (Russell and Smith,

1999). This has been attributed to a lack of understanding of patterns in high risk behaviors; being unaware of the risky sexual behaviors that partners are engaged in; lack of knowledge about HIV-related symptoms, and the prevalent perception of non-susceptibility to HIV infection in this population (Siegal, Ravels, and Gorey, 1998)

Summary: Depressive symptoms have been associated with perceived/internalized stigma and also with being in denial. African American women living with HIV are particularly susceptible to feeling stigmatized and experiencing symptoms of depression. Avoidance coping mechanisms such as denial are commonly adopted in this population and may account for the high levels of depression and consequently poor adherence rates and treatment outcomes. Our hypothesis is that this relationship with adherence is mediated by HIV illness perception as shaped by HIV disease and treatment knowledge or lack thereof.

Acceptance of HIV status and control of HIV illness

Acceptance of HIV diagnosis has been identified as a facilitator of medication adherence (Sankar, Luborsky, Schuman and Roberts, 2000; Nam et al., 2008); Konkle-Parker, Erlen and Dubbert, 2008). According to Moitra, Herbert and Forman (2012), and based on the *cognitive appraisal model of stress and coping* (Lazarus and Folkman, 1984) avoidance-based coping strategies (such as denial) may sabotage health promoting behavior (such as medication adherence). They posit therefore that for adherence to ART, a critical factor is the acceptance of HIV diagnosis and the stresses that come with it (Moitra, Herbert and Forman, 2012). They go further to describe the acceptance of HIV status as a process (not automatic) and explain the concept of acceptance as requiring “a willingness to acknowledge the cause of infection, the implications of infection on one’s future, and openness to altering behaviors to fit the

needs of maintaining healthy living” (Moitra, Herbert and Forman (2012). By inference, acceptance of HIV disease is therefore premised on adequate understanding of the etiology of HIV disease and accurate perception of prognosis of HIV illness given the advent of antiretroviral therapy. We therefore posit that transition from a state of denial to that of acceptance is mediated by a change in illness perception which is facilitated by an increase in HIV disease and HIV treatment knowledge.

In addition to illness acceptance, beliefs about how much control one has with regards to their illness, is a critical factor in self-care necessary in chronic conditions like HIV. Most people at diagnosis have pre-shaped perceptions about HIV disease, their expectations of survival and treatment outcomes (Moitra, Herbert and Forman, 2012). These perceptions form the basis for beliefs about how much control one has over their HIV illness. In a study that examined HIV patients who had excellent adherence rates, the belief that one was in control of their HIV illness was associated with higher levels of adherence to ART (Malcolm et al., 2003)

Summary: Acceptance of HIV status has been shown to facilitate adherence to medication adherence, and conversely engagement in avoidance-based coping behavior such as denial has been associated with poorer medication adherence in the general population of those living with HIV (Weaver et al., 2005). However, to the best of our knowledge, there are no studies that have determined the factor(s) mediating change from the state of denial to acceptance of HIV status or factors associated with increased control of HIV illness among African American women living with HIV.

Self-disclosure of HIV status

HIV status self-disclosure has been associated with receiving social support which has also been shown to be positively correlated with desirable health-related

behavior including the improvement of adherence behavior. In the study by Stirratt et al. (2006), the objective was to examine the relationship between self-disclosure of HIV status and adherence to ART. The investigators “hypothesized that greater disclosure would be associated with higher adherence, and that the relationship between disclosure and adherence would be mediated by the provision of practical social support” (Stirratt et al., 2006). The study participants included 215 persons living with HIV who had poor medication adherence rates (>80%). In this sample, 62% was African American. A social networks questionnaire was used to assess the extent of HIV status disclosure to two major categories – family members and personal contacts. Most of the participants reported high rates of disclosure. Greater degree of self-disclosure of HIV status was associated with higher rates of medication adherence in this population. The correlation between ART adherence and two measures of disclosure were statistically significant. These measures were “the percentage of informed family members and the number of informed family members” (Stirratt et al., 2006). While the correlation between number of personal contacts to which HIV status had been disclosed and medication adherence was not statistically significant, it was in the hypothesized direction. Findings from the mediation analysis demonstrated that the relationship between self-disclosure and adherence was not significantly mediated by practical social support. Practical social support in this study was defined as directly encouraging the participant to keep up with their medications. It should be noted that social support in this study did not include other forms such as emotional and informational social support which may be more relevant in medication adherence within the context of chronic disease management like HIV care.

To the best of our knowledge, there have been no studies that have examined the relationship between self-disclosure of HIV status and medication adherence in this specific population. There has been considerable research on self-disclosure among African American women (Black and Miles, 2002; Serovich, ; Owens, 2002; Craft and Reed, 2012). Studies show that disclosure in this population is selective, and the reasons to disclose or not to disclose their HIV status are varied and depend on the category of people (family members, friends, partners, children), and/or perceived closeness to the person in question (Black and Miles, 2002; Sowell et al., 2003). While findings demonstrate that social support especially acceptance from family members is associated with improved medication adherence in this population, the relationship is likely not a direct association (Stirratt et al., 2006). In fact family has also been identified as a source of stress (Owens, 2002).

There is a need to explore other sources of support to determine which may more directly as well as significantly influence adherence behavior. Findings from our preliminary study suggest that *peer support* may have a huge impact on medication adherence in this population.

Finding purpose/relevance

Care-giving role has been associated with improved adherence to medication among African American women living with HIV (Gant and Welch, 2004; Edwards, 2006). Women who have young children have reported a need to do whatever they can to live in order to provide care for their children. This need gives them a sense of relevance and serves as motivation to be adherent to their medication (Prosser, 2011).

Central to the African American woman's faith in God is the belief that God is sovereign and in control of all things (Musgrave, Allen and Allen, 2002). Therefore, life

in this population is viewed as being sustained by a divine power higher than but not necessarily in conflict with the Western science. Findings suggest that living with HIV in this population brings people closer to God While constituting a source of well-being, by aiding in coping with medication side effects and HIV related stress, faith in God likely confers a sense of purpose in life along with a deep sense of morality which facilitates willingness to make life style changes such as substance abuse.

Another context in which this population finds relevance is in engaging in activities to promote HIV awareness and education. In the literature, there are no studies (to the best of our knowledge) that have assessed the relationship between involvement in HIV advocacy activities and medication adherence among African American women living with HIV. In a longitudinal qualitative study by Buseh and Stephen (2006), the objective was to explore the narratives of the HIV-related experiences of African American women living with HIV (n=29) in order to understand their response to HIV associated stigma. For each participant, 10 interviews were conducted over a 2 year period. Findings from this study showed that over time these women transited through different phases in their illness experience with regards to resistance to stigma. These phases included “enlisting support, facing the illness, disclosing only at strategic times, redefining stigma as ignorance, and becoming advocates” (Buseh and Stephen; 2006). Involvement in HIV advocacy activities was the culmination of their defiance of HIV-related stigma. While adherence to medication was not a focus area in this study, HIV-related stigma has been identified as a major barrier to ART adherence (Lichtenstein, 2003). HIV advocacy has been identified as a coping strategy whereby the HIV-positive woman chooses to share her experiences living with

the virus with the objective of conveying the challenges and associated burden of stigma, thereby persuading others to refrain from behaviors that put them at risk of infection. By resisting associated stigma through engagement in HIV advocacy, a sense of relevance and dignity is gained despite living with the virus (Paxton, 2002; Norris and DeMarco, 2005).

Summary: In addition to finding relevance through care-giving role, and finding purpose through faith in God and we hypothesize that those involved in HIV advocacy are likely to be exposed to more HIV related information, have more perceived control over their illness, become more involved in their care and as a consequence, more adherent to their prescribed antiretroviral regimen.

Provider-patient relationship

The relationship between patients and their provider in chronic disease management is considered an important factor in treatment outcomes. In HIV care, patients' perception of engagement with the provider has been associated with better adherence rates (Bakken et al., 2000; Roberts, 2002; Johnson et al., 2006; Schneider et al., 2004). Generally, women are more likely to be adherent to their treatment regimen when they perceive that the relationship they have with their health care providers is positive, they have confidence in the information being provided and they are provided opportunity to take control of their own care (Watkins-Hayes et al., 2012.). In this review of literature, no studies examining the influence of provider-patient relationship on ART adherence specifically among African American women were found. However, there have been studies on racial/ethnic differences in provider-patient interactions in HIV care.

In the study by Saha et al. (2010), the objective was to determine whether trust in one's provider was a mitigating factor in racial disparities in HIV care. Data was collected from 1,104 African American and 201 White patients attending an academic HIV clinic in an urban area. On a 0 – 10 scale, the level of trust that African Americans expressed in their providers (8.9) was lower than that of White patients (9.4; $p < 0.001$). Compared to Whites (92%), African Americans were also less likely to receive ART though eligible (85%; $p = 0.02$); more likely to report non adherence to ART in the three days prior to data collection ($p = 0.005$); and less likely to achieve viral suppression ($p = 0.04$). While there was no association between trust in one's provider and ART receipt or viral suppression, the study found a significant association with trust in one's provider and ART adherence (adjusted OR, 0.40; 95% CI, 0.25-0.66).

Beach et al. (2010) sought to investigate the possibility of racial differences in provider-patient communication with respect to HIV care. In an assessment of provider and patient communication behavior in 354 clinical encounters observed in four HIV treatment sites, coding using the Roter Interactive Analysis System was used to determine that providers were more verbally dominant in their interaction with African American patients compared to White patients. Based on their observations, the investigators report that this was largely attributed to the more passive patient role taken by African Americans. Ratings of provider communication were similar for both African American and White patients, and no racial differences were observed for other measures of communication assessed.

Summary: The provider-patient interaction is critical in the delivery of patient-centered care. Within the African American community, there is evidence that distrust of

the healthcare system still persists; with origins in their historical experience of racism and purposeful exposure to unethical experimentation like the Tuskegee Study, in addition to current experience of racial discrimination (Dwayne, 2005; Thrasher et al. 2008). Women living with HIV from this community also have low socio-economic status and have low educational attainment. This group may tend to adopt a more passive role in their care when they feel that the provider does not genuinely care and/or is not acting in their best interest.

Substance abuse

Substance abuse has been associated with non-adherence to antiretroviral medications among persons living with HIV (Turner et al., 2007) and has been found to predict non-adherence behavior in African American women living with HIV (Tanya et al., 2004; Cohen et al., 2004; Ahdieh-Grant et al., 2005; Cook et al., 2007; Lazo et al., 2007). In one study, data was collected over a three year period (July 1997 – December 2000) as part of the Supplement to HIV and AIDS Surveillance (SHAS) project. The objectives were to determine whether African American women living with HIV reported more crack cocaine use than women of other racial/ethnic backgrounds. The study also examined the association between self-reported crack cocaine use and antiretroviral adherence (Tanya et al., 2004). The sample of women included in the analysis was stratified into three categories characterized by history of drug use. These included “non-users”, “other drug users”, and “crack users”, with drug use defined as use in the preceding 5 year period. Out of a sample of 1655 women included in the study, 72% (1193) were African American, 18% (298) were White and 8% (129) were Hispanic. Of the 376 women who self-reported the use of crack cocaine, 81% (306) were African American. Further analysis on this population found that those who reported drug use

were less likely to adhere to their antiretroviral regimen when compared to drug non users. Multivariate analysis was employed to control for potential confounders such as age, education, income level, marital status, and number of antiretroviral drugs in the prescribed regimen.

In the study by Ahdieh-Grant et al. (2005), data from the Women's Interagency HIV Study (WIHS) was analyzed to "characterize temporal trends in discontinuation of HAART" (Ahdieh-Grant et al., 2005). The WIHS is a cohort study, prospectively following women living with HIV to observe the natural history of the disease. Following baseline data collection, participants were interviewed every 6 months. Ascertainment of viral load and CD4 count were determined by blood specimens, while HAART discontinuation was determined from the first report of not taking prescribed ART for at least 6 months. Calendar-stratified analysis found that, African American women (compared to White women) and injection drug use were significantly associated with discontinuation of ART within the first calendar period.

Cohen et al., also used the WIHS data to examine "the prevalence and characteristics of HIV-positive women who do not report HAART use" in spite of medical eligibility (Cohen et al., 2004). Using a standardized interview-based survey, data were collected on the following factors every 6 months – demographics, medical history, psychosocial history, sexual history, tobacco use, alcohol use, illicit drug use and reasons for non-adherence to medications. Use of HAART was by self-report. Using analysis of variance, significant differences between those taking HAART, those not taking HAART though prescribed, and those not prescribed ART were tested. Chi-square was used to determine the association between current illicit drug use and

HAART. Findings indicated that comparatively, a significantly lower proportion of African American women were taking HAART. Drug use (both past and current) was associated with not taking HAART. Women using illicit drugs were more than twice as likely to report not using HAART even when prescribed [OR = 2.1; 95% CI: 1.17 – 3.79].

Cook et al. (2007) investigated the association between illicit drug use and depressive symptoms, and how this affected antiretroviral medication use among women with HIV/AIDS. Participants were drawn from six states (n = 1710) data collected by interviews conducted every six months. They found interactive effects between illicit drug use and depressive symptoms with resulting non adherence to HAART. Another interesting find in this study was that while use of illicit drugs in the absence of depressive symptoms was significantly associated with non- adherence, depressive symptoms without illicit drug use was not associated with non-adherence. These findings demonstrate that there is an association among depression, substance abuse and medication adherence. They also found that lower HAART adherence was more prevalent among African American women as well as substance abuse and depression.

In a study by Sharpe et al.(2004), interview data collected from 1655 HIV–positive women was analyzed to investigate the effect of crack cocaine use on adherence to ART among African American women (Sharpe et al., 2004). Of the 1655 participants, 1196 (72%) were African American. Of this number, 306 (26%) were crack cocaine users. Using logistic regression analysis to control for age and education in the African American sub-sample, the investigators examined the effect of crack cocaine use on HIV medication adherence in this sub-population (OR = 0.37; 95% CI = 0.24-

0.56). Findings from a multivariate analysis showed that those who used crack cocaine and other illicit drugs were less likely to adhere to their prescribed ART regimen compared to those who were non-drug users (OR = 0.47; 95% CI = 0.36-0.68). Clearly, among women living with HIV, illicit drug use is more prevalent in African American women and poorer adherence to ART as a consequence of substance abuse.

Summary: Findings from these studies support the association between substance abuse and adherence to ART while also demonstrating that comparatively a significant proportion of African American women living with HIV are engaged in illicit drug use and alcohol consumption. Depressive symptoms have also been linked to substance abuse (Cook et al., 2007). What these studies do not show is the underlying reason(s) why these women take to drugs. The assumption is that drug/ alcohol use is a predisposing factor in HIV infection in this population and that substance abuse is continued as a previously developed addictive behavior which then becomes a barrier in medication adherence. However, findings from our preliminary study suggest that those who take illicit substances and/or alcohol in this population are not all previous users. It is important therefore to (1.) determine the proportion of African American women living with HIV who start drug/alcohol use following HIV diagnosis and (2.) distinguish between substance abuse as an addiction and the adoption of substance abuse as a coping mechanism.

Peer support

Social support can be of different forms. In the literature, there are generally five broad categories of social support that are commonly cited. According to Glanz, Rimer and Lewis (2002) social support categories include and are defined as follows –

1. Instrumental support - “tangible aid and service”.

2. Emotional support – “expressions of empathy, love, trust, and caring”.
3. Informational support – “advice, suggestions, and information”.
4. Appraisal support – “information that is useful for self-evaluation”.
5. *Affiliational support – refers to the conveyance that one is inclusive in a “social network of reciprocal help or mutual obligation” (Cohen, 1985; Dutcher et al., 2011).

Most studies on social support for African American women typically found instrumental and emotional social support as the common types of support received from others usually family members, children, partners, friends, and other personal contacts within the community (Owens, 2003; Edwards, 2006). While these are necessary for the general wellbeing and health related quality of life for those living with HIV, their effect on medication adherence may be limited and indirect. Although persons giving social support as mentioned above may be able to express empathy, show concern, and offer tangible aid, they may not be in the position to

- i. offer useful information on antiretroviral medication use and expected outcomes;
- ii. give advice about strategies to deal with the challenges associated with chronic medication use; or
- iii. make suggestions about ways to stay adherent to prescribed regimen.

Peer-based support has been shown to enhance health care in the management of chronic conditions (Dutcher et al., 2011). Benefits include facilitating access to health care services, providing social support, and increasing involvement in self-care and self efficacy in performing specific health-related tasks. The basis for using peers in promoting health-related behavior is that the peers have similar characteristics and experiences with the target population, which strategically positions and enables them to provide much needed support and mentorship (Anderson, 1996; HRSA, 2005).

In a qualitative explorative study by Dutcher et al. (2011), 23 in-depth interviews were conducted to examine “the roles and activities of peers working in HIV care and

treatment, in the context of social support”. Participants were recruited through the Peer Education and Training Sites/Resource and Evaluation Center (PETS/REC) initiative. Participants were persons living with HIV who had been trained to serve as peers to facilitate linkage to care and antiretroviral treatment. One of the focus areas of the interview was the peers’ assessment of the impact of their interaction with clients on “HIV knowledge, access to health care, utilization of services, adherence to treatment, and provider relationships. Eighteen (78%) out of the 23 participants were African American, and 15 (65%) were women. According to the participants, the principal factor that facilitated a connectedness with their clients and established credibility was the disclosure of their shared HIV status and related experiences. Issues directly and indirectly related to HIV care and ART were targeted based on assessment of client’s needs. Activities described by the peers were categorized by type of social support (Table 4-5). Informational support offered included helping clients navigate the health care system, education on medical information about HIV and aiding comprehension/clarification of medical information given by healthcare providers. However, the most frequent activity in this category was explaining to clients the critical role of medication adherence in their health care and outcomes. Peers also shared information on how to manage medication side effects. Instrumental support included reminding clients of appointment, providing transportation for clinic appointments, ordering medication refills and referrals to other resources such as substance abuse support. Participants reported that they employed a flexible approach; catering to each client based on need. With respect to medication adherence, peers reported giving different types of support based on the client’s position on the continuum of their HIV illness experience. For example,

newly diagnosed clients were given emotional support to facilitate acceptance of status and informational support to enable involvement in self-care.

Summary: Findings from these studies suggest that peer support may provide more relevant social support needed to enable adherence to ART. While social support from family, friends and community have been associated with improved medication adherence, the relationship is indirect and has more to do with acquiring better coping skills and improvement in psychological well-being. Peer support however is shown to have direct impact on medication use behavior and provides an effective strategy for interventions to enhance medication adherence (Broadhead et al., 2002; Raja, McKirnan and Glick, 2007).

Summary of Part I Review

Findings from the preliminary study and corroborated by findings in the literature suggest that the care expectations of this population and the dynamics of the provider-patient relationship may be perceived differently from the “professional” care model. The care expectations of African American women living with HIV are that the health care provider focuses on her as a whole being that needs medical, emotional and spiritual healing and not exclusively on the disease and the physical symptomatology (Bailey, 1987); shows interest in her as a person; shows her respect as a deserving individual and is caring, empathic and sensitive to her concerns. If the care approach fails to meet the expectations of this population, adherence to prescribed treatment may be compromised. Apart from the holistic care from care providers, social support from significant persons in their lives and peer support from others living with HIV can significantly enhance medication adherence in this population.

PART II – Healthcare Provider Perspectives on Medication Adherence

From the findings of the preliminary study with a sample of African American women living with HIV, other research questions emerged to inform this study. Based on the study objectives, a further search of literature was conducted. The aim of the literature search was to find studies that had similar objectives and review their findings.

Comparative Studies: Providers' versus Patients' Perspectives

The search yielded ten studies that compared perceptions of care providers and patients living with HIV/AIDS. Two of the studies were surveys; one study adopted a mixed method approach with both surveys and focus groups. The remaining studies were qualitative studies using interviews and focus group discussions to collect data. The studies are summarized in Table 2.1. Some of the studies reviewed focused on perceptions about HIV care (n = 5) while others assessed perceptions about medication adherence. Those investigating perceived barriers to care looked at entry into care, retention in care, patients' care needs and patient satisfaction with care. None of the comparative studies focused on African Americans as a target population and only one study looked exclusively at women.

In a study by Burns-Tisdale et al. (1994), the objective was to explore best practices and barriers to outpatient HIV care. The investigators found that perceptions among patients differed by gender. While male patient participants recommended improvement in provider communication and reported needs such as transportation and flexibility in clinic appointment scheduling, women expressed such needs like being included in treatment decision making and having a care provider they were familiar with (Burns-Tisdale, Duprat and Wells, 1994). Healthcare providers identified time

constraint in care delivery as a significant barrier. Women were more concerned with personal factors versus inter-personal and structural barriers.

In another study focused on adequacy of care, one of the needs that patients identified as important to them was the maintenance of confidentiality (Beedham and Wilson-Barnett, 1995). The major difference between patients' and providers' perspectives was on the integration of general and specialist care so that patients can receive both HIV and primary care in one setting (primary care). Patients were averse to this care approach. This was in contrast to the findings in the study by Laschinger et al., (2005). In this study patients expressed a preference for a care model where they received most services in the same setting. In both studies, patient perceived barriers to care included non-medical resources such as housing and financial resources.

The study by Schietinger and Daniels (1996) assessed training needs of health care providers from both provider and patient perspectives. In contrast to provider perception of medical training as paramount, patients believed that health care provider (HCP) training should include inter-personal skills, cultural competence and interview skills. Another study with contrasts between provider and patient perspectives was conducted recently by Bofill et al. (2013). In addition to perceived low self-efficacy, patients identified provider and health care system factors as limitations while providers defined the patient role as including taking responsibility for medication adherence and cited lack of patient commitment as a limitation to achieving adherence. In this study, both providers and patients agreed that chronic management, substance addiction and the provider-patient relationship were associated with HIV related health behaviors including entry into care, retention and medication adherence.

There were contrasting views between providers (pharmacists) and patients in a study exploring challenges to medication adherence (Jallow et al., 2007). Issues that were considered significant to patients were not prioritized by pharmacists in the survey. These included difficulty in swallowing pills, side effects like dry skin, concerns about drug toxicities, and particularly concerns about privacy when their medications were dispensed at the pharmacy.

Abel and Painter (2003) looked exclusively at barriers to medication adherence in the female population living with HIV. There was concordance in provider and patient views about the provider-patient relationship and simpler regimen as facilitators. However, most other factors identified by patients were different from those cited by providers. One major barrier from the provider perspective was the inundation of patients with information at the time of diagnosis. Patients in another study by Alfonso et al. (2009) also reported information 'overload' as a problem.

Both providers and patients agree that medication-related factors continue to be challenges for patients living with HIV. Dosing frequency was similarly cited by providers and patients in a study by Savini et al. (2003). In an all-male patient population on multi-drug rescue therapy (MDRT), a supportive relationship with provider and patient education were considered some of the facilitators (Alfonso et al., 2009). Patient education was said to enhance understanding of treatment, and thus help prepare patient for treatment initiation (Alfonso et al., 2009).

In one study, patients and providers were required to rate adherence following a clinical trial (Cox, 2009). While providers tended to rate those with a job as more adherent, patients who rated themselves as adherent tended to be those with more

social support, suggesting that social support may be a more significant facilitator in medication adherence than financial security.

Care Provider Perspectives

In the literature, five studies that looked at provider perceptions of barriers to care in patient populations living with HIV were found. Two of the studies had a mixture of providers (physicians, nurses, etc.), one was with pharmacists only; another with healthcare workers in South Africa and the fifth with a variety of stakeholders including non-medical personnel, and this one was specific to African American women.

The major barriers to care identified in one of the studies that exclusively assessed African American providers was access to care (specialty, primary and non-clinical services) and access to financial resources (Lee-Ougu et al., 2003). Focus groups and surveys were used to determine provider perceptions on barriers to care and needs of Minority HIV-positive patients.

The study by Valverde and colleagues (2006) focused on identifying provider-related characteristics that constituted barriers to care in HIV positive patients. Findings from this study suggest that there are racial/ ethnic and gender differences in provider perceptions of barriers to HIV care (Table 3-2). The perceptions of healthcare providers from minority populations were more consistent with perceptions of patients from vulnerable populations, including minorities. This study, focusing on African American women, was more or less a needs assessment seeking to provide insight into issues affecting these women, and was intended to inform culturally relevant interventions (both prevention and treatment) for this population (National Alliance of State and Territorial AIDS Directors, 2010). Stakeholders including persons living with HIV were invited to participate in focus groups conducted across six states. The objective was not

to compare perceptions between providers and patients but to identify key factors that made this population vulnerable to HIV and barriers to care for those infected. A major theme in this study was the complexity of the lives of members of the target population. Sub-themes included sexual abuse, violence, substance use and mental health. The authors suggested that HIV interventions for this population should be targeted based on their unique context.

In a study by Kibicho and Owczarzak (2011), 19 pharmacists were interviewed to assess their perceptions of barriers to antiretroviral adherence. The barriers identified were in three categories - patient-specific, treatment-related, and structural level factors. Again, issues such as substance abuse and mental health came up as barriers, suggesting that these problems are not unique to African American women.

One of the studies reviewed was conducted in South Africa where the context of the disease and the challenges are different (Coetzee, Kagee and Vermeulen, 2011). However, transportation was again reported as a major structural barrier; demonstrating that universally, transportation is a key facilitator of access to HIV care.

Care Gaps: Current Practice versus the Ideal

Two studies assessed gaps between current care practices and what should actually occur in practice. In the study by Rief and colleagues (2003), HIV case managers were surveyed to assess their adherence to their counseling practices. Most respondents agreed that as part of their job, they were required to counsel their clients on medication adherence. However their counseling activities centered more on monitoring of medication use. About a third of respondents also acknowledged their perceived inadequacy in medication adherence skills.

Another study assessed providers' perception of support activities they considered important to patients' medication adherence and compared this to their self-reported adherence to providing these activities (Park-Wyllie, Kam and Bayoumi, 2009). For a large proportion, endorsing an activity did not readily translate to providing the said support activity. Providers identified barriers such as lack of time in fulfilling support activities.

Summary of Part II Review

From the studies reviewed, it is evident that providers' and patients' perspectives about factors that affect HIV care and medication adherence are not always similar. Efforts by the healthcare system to focus on problems perceived as significant barriers to care may not yield optimal results if patient perceived barriers are not taken into account. While there are challenges that most persons living with HIV generally face (like transportation), there are barriers that are specific to sub-populations based on their history, culture, social context and even gender.

In the studies reviewed, health care providers as professionals are generally more perceptive of factors that are more structural than personal to the patient. Again, when providers identify similar problems as patients, the order of importance may not be the same as seen in the study by Jallow et al. (2007). In implementing interventions, if patient perspectives are not taken into account, efforts may be channeled to areas of less impact resulting in inefficient allocation of limited resources. Conversely, providers' perspectives capture factors that patients may not be aware limit their ability to access care (for example access to financial resources), and if these are not addressed, treatment goals may not be achieved.

Table 2-1. Comparative studies on providers' and patients' perspectives

Author(s)	Date	Aims	Methods	Results
Burns-Tisdale, Duprat and Wells	1994	To explore best practices and barriers to patient care in an outpatient setting	3 Focus group discussions (FGDs): Men living with HIV, women living with HIV, healthcare providers	<p><i>Men:</i> <i>Commendations:</i> [1.] Provider commitment to patient; [2.] sensitivity to and awareness of issues relevant to patient; and [3.] respect for patient <i>Recommendations:</i> [1.] Improvement in provider-patient communication [2.] transportation; and [3.] flexibility in scheduling appointments</p> <p><i>Women's needs</i> [1.] inclusion in treatment decision making; [2.] familiar care provider; and Integration of gynecological and primary care.</p> <p><i>Healthcare providers' perceived barrier:</i> Time constraint in care delivery</p>
Beedham and Wilson-Barnett	1995	To examine clients' views on adequacy of care compared to views of care providers	Interviews of clients (n=85) and health care providers	<p><i>Patient perceptions</i> [1.] appreciation/ satisfaction with care; [2.] patients' financial lack and social deprivation as barrier; [3.] Need for better housing; [4.] Confidentiality of patient records; and [5.] perceived prejudice/ discrimination</p> <p><i>Major contrast</i> <i>Clients:</i> Keeping general and specialty care separate to maintain confidentiality and receive expert care. <i>Providers:</i> Integrating general and specialty care</p>

Table 2-1. Continued

Author(s)	Date	Aims	Methods	Results
Schietinger and Daniels	1996	To assess the training needs of healthcare providers (HCPs) in HIV service organizations and public health clinics; and the needs of PLWHIV receiving care from HCPs	Interviews conducted with select key informants among HCPs and a wide range of PLWHIVs.	<i>HCPs perception of training needs:</i> Medical information as primary training need. <i>Patient perception of training needs:</i> In addition – inter-personal skills, cultural competence, sensitivity to substance abuse, establishing rapport, maintaining confidentiality, interview skills
Abel, and Painter	2003	To explore factors that influence antiretroviral medication adherence for women living with HIV/AIDS from patient and HCP perspectives	Two focus groups – for patients (n=6) and HCPs (n=6) respectively	<i>Patient perceptions:</i> <i>Facilitators:</i> 1. Belief in treatment efficacy; 2. Memory prompts; 3. Provider-patient communication; and 4. Simpler regimen. <i>Barriers:</i> 1. Emotional trauma; 2. Perceived stigma; 3. Side effects; and 4. Changes in regimen. <i>HCP perceptions:</i> <i>Facilitators:</i> 1. Provider-provider relationship; 2. Tailored patient education/ individualized care; and 3. Patient involvement in decision-making <i>Barriers:</i> 1. Complexity of regimen; 2. Lack of patient involvement in care-related decision-making; and 3. Providers' insensitivity to patients' challenges; and 4. Inundation with information at diagnosis causing patient to tune out and not remember details on treatment initiation (<i>perceived as major barrier</i>).

Table 2-1. Continued

Author(s)	Date	Aims	Methods	Results
Savini, James and DiGuglielmo	2003	To determine 1)if present clinicians' perception differ from the perceptions of clinicians studied in the Gallant and Block study (1998); 2) if current patients' perception differ from the perceptions of the patient population in the Gallant and Block study; and 3)if the differences in clinicians' and patients' perceptions in the Gallant and Block study currently exist.	Survey of 15 clinicians (physicians, HIV nurses, nurse practitioners) Survey of patients (n=100)	Present clinicians - complexity of medication schedule - dosing frequency - large pill burden Current patients -Side effects - dosing frequency
Laschinger, Van Manen, Stevenson and Fothergill-Bourbonnais	2005	To describe and compare the perceptions of ideal and current care practices of health care providers and PLWHIV	8 Focus group discussions (of 6 -8 respondents) for PLWHIV and 7 FGDs for care providers	Common themes across FGDs 1)Patient-centered and holistic care [communication, collaboration, compassion, respect, support] 2) Access to care -access to medications and treatments - follow-up and monitoring of care - Patient education - Resources [financial, housing, transportation] "one-stop shopping – having as many services as possible in one setting

Table 2-1. Continued

Author(s)	Date	Aims	Methods	Results
Jallow, Källemark-Sporrong, Walther-Jallow, Persson, Hellgren, Ericsson	2007	1) To identify major challenges experienced by pharmacy staff in HIV care delivery; 2) to identify pharmacy staff perceptions of patient-related concerns with ART; and 3) to compare pharmacy staff and patients' perceptions about challenges patients experience associated with ART.	Administration of questionnaires to both pharmacy staff (n=70) and patients (n=195); using the <i>Problem detection study</i> approach	Pharmacy staff did not recognize and prioritize as barriers some of the challenges patients indicated as important including – difficulty in swallowing pills, dry skin from medication, concerns about toxicity of medication, worry about public exposure of status and thus disturbed by display of medication on pharmacy counter.
Alfonso, Toulson, Bermbach, Erskine, Montaner	2009	To describe the experience of PLWHIV on multi-drug rescue therapy [MDRT] and their HCPs including perceptions of challenges and facilitators to adherence; and provider and patient roles in the care process	Interviews with 12 patients (all male volunteers; 11 Caucasian and 1 Asian) and 7 HCPs (one physician, one nurse, one pharmacist, two social workers, and one receptionist)	Emerging themes: [1.] Treatment factors (side effects, pill burden, toxicities, co-morbidities, outcome expectancies) [2.] supportive relationship (respect, understanding, collaboration); [3.] information exchange, (<i>patient perception</i> – information “overload”/ redundancy) and [4.] readiness for treatment (preparedness including adequate education and understanding of treatment and willingness to commit to adherence)

Table 2-1. Continued

Author(s)	Date	Aims	Methods	Results
Cox	2009	To evaluate the PLWHIV and their clinicians' perceptions of medication adherence and clinic visit attendance in association with lifestyle, psychosocial and health belief model (HBM) variables.	Data from an AIDS clinical trial was analyzed. Baseline information collected by questionnaire and patient self-report.	-After 12 months, adherence with follow-up visits associated with older age. <i>Clinicians' rating of patients' adherence:</i> adherence significantly associated with being older, being employed and enrolled in clinical trial for altruistic reasons. <i>Patients' ratings of self:</i> significantly associated with being older, having family member or friend living with HIV, and considering enrollment in study worth while
Bofill, Lopez, Dorigo, Bordato, Lucas, Cabanillas, Sued, Cahn, Cassetti, Weiss, and Jones	2013	To explore and identify factors associated with patient entry into and retention in care (including adherence) in public and private HIV care facilities from patients' and providers' perspectives.	Key informant interviews (n=12) and FGDs (n=4)	<i>Contrasting perceptions</i> <i>Patients:</i> 1. Low self-efficacy; 2. Fear and concerns about HIV; 3. lack of provider involvement in treatment; 4. Health care system limitations <i>Provider:</i> Provider as decision-maker and patient as responsible for non-adherence. 1. Lack of patient commitment; and medication side effects. <i>Concordance:</i> Chronic illness, substance addiction, and provider-patient relationship (trust, honesty, communication)

Table 2-2. Studies on care provider perceptions

Author(s)	Date	Aims	Methods	Results
Valverde, Waldrop-Valverde, Anderson-Mahoney, Loughlin, Del Rion, Metsch and Gardner	2006	To assess medical care providers' perceptions of the barriers to HIV care and identify associated provider characteristics	Survey (by mail) of HIV medical care providers in Atlanta, Baltimore, Los Angeles, and Miami [physicians, physician assistants, nurse practitioners] (n=420)	<i>Racial/ethnic differences in perceptions:</i> Unavailability of childcare, clinic location/ services inconvenient, and unfriendly Healthcare system considered more important barriers by African American and Hispanic providers compared to Caucasian providers and consistent with perceptions of PLWHIV from disadvantaged populations. →Mental health problems, transportation, and clinic location/ services inconvenient considered more important by female providers compared to male counterparts
National Alliance of State and Territorial AIDS Directors	2010	To provide some perspective on issues and suggestions from persons living with and affected by HIV for the consideration by health departments in the design targeting and implementation of culturally relevant programs for African American women	Semi-structured focus group interviews of stakeholders in six states; minimum of 3 FGDs per state of health department staff, community service providers or consumers of service respectively. Group size : 3 – 18participants	<i>Major themes and Findings:</i> 1. Complexity of African American women's lives -history, culture, faith and family - sexuality and sexual communication - impact of abuse and violence -stigma and disclosure - dependency - perceived risk -substance use and mental health 2. Considerations and strategies from consumers and providers - Holistic and support group - Affordable housing, - Transportation - Prevention messages, media and social marketing - comprehensive sex ed. - provider education -Community collaborations and partnerships (also faith based organizations) -Targeted interventions - Advocacy - Involvement of target group in decision making in community planning groups

Table 2-2. Continued

Author(s)	Date	Aims	Methods	Results
Kibicho, and Owczarzak	2011	To assess pharmacists' perceptions of barriers to medication adherence among PLWHIV and describe strategies to enhance medication adherence in this patient population	In-depth interviews using a semi-structured guide (n=19)	Barriers identified - <i>Patient-specific factors:</i> cognitive, health literacy related, lack of social support, psychological, mental health, and substance abuse <i>Treatment-related factors:</i> adverse effects, intolerable medications, polypharmacy, unresolved medication-related issues. <i>Structural-level factors:</i> provider-patient relationship, depersonalized health care system
Coetzee, Kagee, and Vermeulen	2011	To examine the major structural barriers to ART adherence from the healthcare workers' perspective in South Africa		<i>Main barrier:</i> Stigma <i>Others:</i> Willful non-adherence to receive disability benefits tied to low CD4 count; transportation, food security
Lee-Ougu, Boekeloo, Thompson, Funnyé, Jackson, ShuTangyle, and McNeil	2003	"To learn about African American providers' perception of 1)the causes of clinical outcomes in Minority HIV-infected patients, 2) barriers to effective HIV care delivery, and 3) priority training and technical assistance needs"	Focus group discussions between health professionals (nurses/nurse practitioners, physicians, physician assistants, dentists and clinical pharmacists; n=266) and mailed surveys (to primary medical care organization; n=28)	FGDs: Emerging themes were: -provider cultural competency, -access to financial linkages, and - access to comprehensive care services Surveys: -funding/ financial resources -access to specialty referrals -accessibility of primary care -access to non-clinical

Table 2-3. Current practice versus perceived “ideal”

Author(s)	Date	Aims	Methods	Results
Reif, Smith, Golin	2003	To examine adherence-related practices and attitudes of case managers to their medication adherence counseling practices.	Survey returned by 94 out of 111 administered.	Majority (65%) reported discussing medications with almost all their clients. Counseling on adherence-related behavior most frequently provided was focused more on medication use monitoring than on instruction on medication use. Most respondents (77%) believed that medication adherence counseling was part of their role, but a good proportion (36%) did not perceive themselves as having adequate skills to do so.
Park-Wyllie, Kam, Bayoumi	2009	To assess the concordance between clinician perspectives on the importance of support activities to antiretroviral adherence and clinicians' self-reported actual adherence to these activities in practice.	Survey (84-item) mailed to physicians, pharmacists and nurses highly specialized in and providing HIV care. Respondents asked to rate 30 types of adherence support activities on a 5-point scale. (n=169; response rate of 56%)	Respondents agreed that most adherence support activities listed should be provided to patients (24 out of 30 endorsed by the majority). Adherence gap (31% -75%) determined by proportion of healthcare providers not providing adherence support activity even though they endorse it as necessary for the patient. <i>Barriers identified:</i> 1. Lack of time (32%); 2. Unavailability of healthcare professionals to refer patients to for adherence support (25%); and 3. insufficient reimbursement (12%).

CHAPTER 3 METHODS

This chapter includes a review of the epistemology, the theoretical perspective taken and the methodology governing the methods adopted in the research design. The methods used in conducting the research, the criteria for evaluating study rigor, and steps taken to protect human subjects are described. Also included is a reflexivity note, detailing the researcher's assumptions, prior to the study.

Methodological Approach – Grounded Theory and Thematic Analysis

To achieve the study objective, qualitative research methods were employed. The methodological approach chosen for this study was *Grounded Theory*. This approach was considered appropriate given the purpose of the study and the specific objectives addressed. Grounded theory is a qualitative method of inquiry useful in investigating social phenomena. It was developed in the late 1960s (Glaser and Strauss, 1967). As a qualitative research method, the focus of grounded theory is the creation of conceptual frameworks or theories based on inductive analysis of data. The intent of this investigative process is to go beyond merely describing a phenomenon, to gaining a more conceptual or theoretical understanding (Charmaz, 2006). Using this approach, theories generated are said to be “grounded” in participants' perceptions and/or experiences as captured in the data collected. However, for the scope of work covered in this dissertation research and based on the specific study objectives addressed and reported here, data analysis was mostly at the thematic analytical phase. Thematic analysis is a process that is implicit in most qualitative data analysis including grounded theory (Boyatzis, 1998). It involves the coding and categorization of qualitative data with the purpose of identifying patterns and developing themes.

The model generated from provider perceptions was based on the major categories and themes identified through the thematic analysis. At this point in the research, it is considered a preliminary conceptual model but provides a general framework that identifies the numerous issues associated with linkage to care and medication adherence in the target population based on care provider perceptions. Further conceptual data analysis will focus on different parts of this model. Ultimately, the long-term goal of the research is the emergence of theories and/or theoretical models that are more explanatory than descriptive.

Characteristic Features of Grounded Theory

There are key characteristics in the grounded theory methodology. These include –

1. The simultaneous collection of data and data analysis: This is an iterative research design whereby data is collected, analyzed and the findings inform subsequent data collection.
2. The use of codes and categories developed from the data: To code and categorize data, the data is first explored and the codes developed from participants' narratives. Codes are not predetermined based on prior knowledge of the phenomena under investigation or researcher's experience.
3. The development of theory to explain behavior or process under investigation: The ultimate goal in using grounded theory is the development of theory.
4. The use of memos or analytic notes to build theory: Memo-writing is an integral part of the analytical process and facilitates the construction of theory.
5. Theoretical sampling of participants: Concurrent data analysis reveals gaps and informs the choice of other participants to interview for further insight.
6. An initial brief literature review (for sensitization in area of interest) followed later by a broader review of literature specific to the concepts identified in the data.
7. The constant comparison of the data throughout the analytic process: This is the core principle of data analysis in grounded theory. Themes, categories and theoretical concepts emerging are compared with fresh data for similarities and differences. (Glaser and Strauss, 1967; Charmaz, 2004)

Epistemological position: Social Constructionism and Symbolic Interaction

Epistemology is defined as “the possible ways of gaining knowledge of social reality, whatever it is understood to be. In short, claims about how what is assumed to exist can be known” (Blaikie, 2000, p. 8). This is simply the assumption underlying the research; governing the methodological approach and the methods adopted.

The premise of grounded theory as a methodology is social constructionism and symbolic interactionism. These are theoretical perspectives that are based on the following assumptions –

- i. That what people view as real (i.e. their social realities) are created by individual and collective actions; and
- ii. That [these] realities are constructed through the interactions between meanings and actions (Charmaz, 2006).

Based on these perspectives a theory generated using this approach (grounded theory) can be described as an interpretative construction of reality. This makes the approach particularly useful for investigating complex social constructs or phenomenon. Again, this is especially relevant to this study considering the complex nature of care-seeking and medication adherence behavior.

Theoretical Perspective

Over time, multiple versions of grounded theory as a methodology have evolved - some adhering to a pragmatist research approach, and others taking on a more positivist approach (Charmaz, 2006; Glaser and Strauss, 1967). Pragmatism is a philosophical outlook that approaches problem solving in a logical and reasonable way based on specific situations rather than theories or ideologies. The positivism paradigm assumes that there is a “truth” (valid knowledge) and that this truth is based on verifiable and observable measurements.

With further evolution of the grounded theory methodology, Strauss and Charmaz adopted a constructivist approach; the underlying assumption being that theories are not discoveries in the data, but are constructions based on the shared interpretation of the data by researchers' interactions with the participants and their context (Charmaz, 2006). Constructivist grounded theory is therefore an interpretative approach seeking to explain the basis of and reasons behind participants' construction of meaning and action by exploring their perception of phenomena relative to their broader social context (Charmaz, 2006). This study takes on a constructivist approach in the application of grounded theory.

Grounded theory is particularly useful when the purpose of the investigation is the understanding of social processes. Thus, this approach was considered suitable in exploring the perspectives and experiences of health care providers who interact with African American women living with HIV/AIDS to contribute further insight into their care-seeking and adherence behaviors.

Grounded Theory: Strengths and Limitations

Limitations

The relative subjectivity of the data analysis and interpretation limits the use of grounded theory and indeed any type of qualitative method in research where the purpose is to establish causality. Therefore, grounded theory is not suitable nor is it recommended for studies that seek to confirm or refute hypothesized causal relationships. Quantitative methods such as randomized controlled trials and observational studies are more appropriate in such cases. In this study, the efficacy of antiretroviral therapy has already been established and medication adherence shown to be positively correlated with HIV-related health outcomes. The problem is that despite

these advances in medical treatment, a large proportion of persons in this population are either not in care or have difficulty staying on their treatment, and the question is *“Why do persons in this population take or not take their medications?”* A more qualitative method of inquiry is therefore appropriate.

Reliability and validity of the approaches and findings are difficult to establish. However, researchers using grounded theory can enhance rigor in their study and trustworthiness of their findings by ensuring credibility, confirmability, dependability and transferability (discussed in the section on scientific rigor/integrity).

The sampling method and relatively small sample size characteristic of this method, though appropriate for the study purpose, limits the generalizability of findings to other populations. However, hypothesis can be generated and tested with quantitative methods to confirm applicability beyond the locale of the study sample.

Because of the inductive process of data analysis, it is difficult to avoid bias introduced by the researcher. To minimize this, researchers are encouraged to write a reflexivity statement detailing all their assumptions about the phenomena under investigation and also write extensive analytical notes (memos) to aid in differentiating between personal perceptions and what the data actually reflects. Peer review by colleagues and experts in qualitative research; and verification of findings by members of the target population can also help to minimize bias.

The methods of data collection and data analysis can be time consuming and the amount of data can be overwhelming. However, there is a variety of software available that are useful in sorting and organizing data to make it easier to handle and analyze.

The presentation of findings from a study using grounded theory can be quite difficult because of the qualitative nature. The challenge is to translate findings into a form that is useful for application (example in practice or for an intervention).

Strengths

Grounded theory is useful for gaining valuable insight in areas where much is not known. As with most social processes and behavior, these change as contexts change, thus even when an area has been studied, changing contexts may lead to new insights emerging since research is conducted without *a priori* assumptions.

The research procedure is rigorous and systematic. When well done, the analytical steps underlying construction of theory is usually well laid out. This enhances the trustworthiness of the findings.

The method of data collection (in-depth interviews using open-ended questions and probes) generates very rich data capturing the essence of participants' perceptions and experiences. The depth of information that can be obtained by using this method is usually not obtainable with quantitative methods or less rigorous qualitative methods. Hence it is appropriate in investigating the 'how's and 'why's of complex behavior like medication adherence.

Research Strategy

Study Objectives

The care process following HIV diagnosis starts with linkage to a facility that provides HIV clinical care. Appropriate evaluation then determines initiation of antiretroviral therapy. The treatment outcome thereafter is largely a result of the patient's adherence to the prescribed regimen which is invariably associated with retention in care. Treatment outcome is also likely to reinforce adherence behavior. The

preliminary study for this dissertation explored the perceptions and experiences of African American women living with HIV and how the factors identified influence linkage to care and antiretroviral medication adherence.

The illness perception and illness experience of African American women living with HIV were shown to have significant influence on initial response to HIV diagnosis and subsequently adherence to antiretroviral treatment. The conceptual model derived also identified possible mechanisms by which various factors – patient-related, provider-related and structural (healthcare system) – interact to influence linkage to HIV care and medication adherence behavior.

Building on the preliminary study, this doctoral dissertation focused on deriving a comparative conceptual model based on health care provider perceptions and experiences on factors that influence linkage to care and medication adherence among African American women living with HIV/AIDS. The purpose of the study was to determine the concordance between patient perceived factors and provider perceived factors that determine early linkage to HIV care and influence medication adherence in this population. For this study, health care providers referred to physicians, pharmacists, nurses and case managers.

Research findings suggest that there is lack of concordance between healthcare provider perceptions of what needs to be done to enhance patients' medication adherence and what actually happens in practice (Park-Wyllie, Kam and Bayoumi, 2009; Rief, Smith, and Golin, 2003). This dissertation further assessed health care provider perceptions of clients' medication adherence needs and current health care practices that facilitate adherence behavior in the target population.

The study objectives were –

1. To derive a comparative model of medication adherence behavior of African American women living with HIV/AIDS based on health care provider perceptions and experiences.
2. To compare patient perceptions and health care provider perceptions of factors that help to facilitate early linkage of African American women newly diagnosed with HIV to care.
3. To compare patient perceptions and health care provider perceptions of factors that influence medication adherence behavior of African American women living with HIV/AIDS.
4. To explore differences between health care provider perceptions of medication adherence needs of African American women living with HIV/AIDS and current HIV care practices.

Eligibility/Inclusion Criteria

To be included in the study, the participant had to be

- a physician, nurse, pharmacist, or HIV case manager;
- currently providing/ have provided care to clients living with HIV/AIDS for at least 6 months within the previous one year period;
- currently providing/ have provided care to at least five (5) African American women living with HIV/AIDS within the previous one year period; and
- currently working / have worked in a health facility offering HIV services and located within area 3/13 (North Central Florida) within the previous one year period.

Recruitment and Sampling

Florida as a state is divided into 15 geographical regions. With regards to HIV/AIDS care delivery, North Central Florida is covered by areas 3 and 13 (known as area 3/13). This consists of 15 counties that are mostly rural and semi-rural based on their population density (Figure 3-1 and Table 3-1). The counties include Alachua, Bradford, Citrus, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Lake, Levy, Marion, Putnam, Sumter, Suwannee and Union counties. Area 3/13 covers approximately 20

percent of Florida's land area and 7.7 percent of the state's population live within this area (Well Florida, 2010).

HIV health care providers (physicians, pharmacists, nurses and case managers) working within area 3/13 (i.e. North Central Florida), who met the eligibility criteria were identified and contacted by phone and/or email and invited to participate in the study. In selecting participants, care was taken to include a diverse sample in terms of type of provider and practice setting. This sampling technique is known as purposeful sampling, and involves the selection of participants using pre-determined specific characteristics. Patton (2002) describes different variations of purposeful sampling. For this study, a snow-balling technique was used. Even though participants from different types of care facilities (academic health center, county health department, private clinics, non-governmental agencies) were targeted for inclusion, actual participation was also dependent on availability and willingness on the part of the care providers. Following the initial interviews, participants were asked to refer the investigator to colleagues who met the eligibility criteria (a "snow-balling" technique). More theoretical sampling required that subsequent participants meet more specific criteria based on gaps in emerging concepts and categories, and this was also done through snow-balling.

Data Collection

The individual interviews were in-depth using a semi-structured interview guide derived from the preliminary findings (Appendix II). For each participant, a convenient time and venue of choice was set up. A copy of the informed consent was sent via email to the participants prior to the interview. This allowed them to read through and understand the purpose of the study and what was required of them, while saving time spent to conduct the actual interview. A hard copy was administered and duly signed

before each interview. A day before the interview, an email reminder was sent to each participant. The response from the participant served as a confirmation of the participant's availability for the scheduled interview.

The interviews were conducted in a private area to ensure confidentiality. All the interviews were audio-recorded with written consent from participants. To collect demographic information, a pre-approved form was given to each participant to check off the options that were most applicable to them (Appendix III). For the interviews, open-ended questions were used and probes for clarification and further investigation (Appendix II). Based on emerging categories from initial interviews, other questions evolved as the interviews progressed (for example, questions about mental health, substance abuse, patient communication, etc.). Interviews were conducted until no new properties of the emerging categories were forthcoming from subsequent interviews. The saturation point was reached after 21 interviews had been conducted.

Before and after each interview, field notes were written by the researcher. The aim of this was to help put data from participants in context and capture non-verbal communication perceived to be relevant to the study. Also included in the field notes were the researcher's thoughts on the interview and areas for questioning when interviewing other participants. Following each interview, the researcher intentionally continued to chat with the participant (except in cases where participants were short of time and had to return to their professional duties). Participants often continued talking after the recording was stopped, and these post-interview chats were equally enlightening. Post-interview information was also written down as field notes and often provided points included for further inquiry in subsequent interviews.

All the audio-recorded interviews were transcribed verbatim. Transcription was done by Landmark Associates, Inc., a professional transcription agency, approved as a vendor by the University of Florida. Audio recordings and transcripts were uploaded to a secure website. The transcripts were spot checked to verify accuracy of transcription. Errors were minimal in all the transcripts (error rate less than 1%).

Data Analysis

Data analysis started once the first interview was conducted and continued throughout the process of data collection. Software developed for qualitative data management and analysis – the MAXQDA 11 (Release 11.0.2) was used to code transcripts, sort and organize data for ease in analysis.

Coding and categorization: Each transcript was imported into the MAXQDA portal for coding and memo writing. An initial line-upon line open coding was done to develop codes used in subsequent transcripts. Over 100 codes were developed from the initial line-by-line and phrase-by-phrase coding of the first transcripts. Code development and refinement continued as new information in subsequent transcripts emerged and newer codes compared to previously developed codes. Memos were written alongside codes as they were developed to explain the premise and meaning of each code (Figure 3-2). The initial coding was followed by more focused coding in subsequent transcripts; resulting in further revision and refining to a total of forty seven codes. For example ‘fear of being abandoned’ (coded initially as *‘being abandoned’*); being ostracized, having one’s status exposed or disclosed were all integrated into the code *‘fear’* (Table 3-1). More conceptual coding led to the generation of themes. For example, from sub-codes under the code ‘access to care’ (transport, cost, linkage and access) came the themes – *availability, affordability, and accessibility*. From the

synthesis of the refined codes and emerging themes, eight major categories were identified. Essentially the themes were sorted and those addressing a similar area were grouped into a category. These categories then formed the building blocks for the conceptual model (*study objective 1*).

Axial coding was used to establish the links between codes and later in the analysis, themes and categories (Strauss and Corbin, 1999). Intersections of codes (indicated by excerpts from transcripts that were assigned more than one code) provided clues to the links between codes and between categories. For example some excerpts of the data were coded '*literacy*' and also '*language barrier*' suggesting that language may be a barrier for patients who have low literacy levels. Associations that were made between themes and categories were also verified by subsequent interviews and later by member checks (showing findings to participants for validation).

In building the model, connecting unidirectional arrows were used to indicate a linear association; implying a transition from one point to another (for example transition from acceptance of HIV status to perceived control of disease in patient's illness experience). Bidirectional arrows were used where transitions were perceived as possibly going either way. For example providers talked about some patients in the target population going back into some state of denial at some point even after having accepted their HIV status; hence transition between denial and acceptance was depicted with a bidirectional arrow. Links without arrows were used to indicate an association. Further data analysis and quantitative research will be conducted to determine the nature of some of these associations (mediating, interacting, "causal"). However, this is beyond the scope of this dissertation.

The conceptual model derived was compared to the model previously developed using a similar analytical technique in the preliminary study. Using the themes and categories, similarities and differences were identified with regards to factors influencing linkage to care and medication adherence in the population of African American women living with HIV/AIDS (*study objectives 2 and 3*). Data (specifically quotes) for similar themes under each category from the respective models were compared and contrasting details identified. For example, while substance abuse was a theme similar to both models, provider perceptions centered round the addiction as both a predisposing factor in acquiring HIV and a continuing behavior that becomes a barrier to medication adherence. However, patient perspectives provide additional insight as some persons in the target population who were non-users (of illicit substances) prior to HIV diagnosis turned to substance abuse as a coping mechanism. In comparing categories between models, gaps were also identified – for example a mediating factor perceived by care providers as relatively prevalent and significant in impacting adherence behavior was mental health. However, this was not specifically identified by patients as a factor in adherence.

Towards the end of each interview, providers were asked about the efficiency of the health care system in providing care to the target population. Further probes included questions about current care processes that were perceived as hindering rather than enhancing care for this population and recommendations that could better meet patients' needs. Analysis of these portions of the transcripts was also used to determine providers' perspectives on the gaps between the current practices associated with HIV care delivery and the perceived care needs of the target population (*study*

objective 4). The responses were reviewed and specific issues and corresponding recommendations identified. All gaps identified are presented in the results section.

Integrity and Protection of Human Subjects

Evaluation Criteria

The criteria set forth by Guba and Lincoln (1989) for evaluating the ‘trustworthiness’ of qualitative studies include – credibility, transferability, dependability and confirmability. These criteria ‘parallel’ those used in evaluating the quality of quantitative research – internal validity, external validity (generalizability), reliability and objectivity.

Similar to establishing internal validity in quantitative research, *credibility* is concerned with ensuring that there is congruence between respondents’ perceptions of their realities and the representations of those realities by the researcher(s) (Lincoln and Guba, 1989). To establish credibility, the researcher seeks to build a relationship with the participants in order to be well acquainted with and gain appreciable insight of their context. In this study, this was done by making previous contact with participants through phone calls and emails, and also engaging in non-research related conversation aimed at becoming familiar with participants’ background and eliciting other relevant information prior to the interview. To ensure that participants’ perspectives were fully explored and captured, the length of the interviews was strictly defined by the ‘flow’ of the interaction during these encounters.

Usually, additional interviews to clarify data may be conducted as required, but this was not necessary in this study. At regular intervals in the research process, de-identified data may be presented to colleagues well acquainted with qualitative research for discussion, critique and/or confirmation of the researcher’s interpretations and

conclusions. The findings were reviewed by a qualitative researcher with expertise in grounded theory methodology. The reviewer evaluated the thematic analysis and categorization of codes and themes. The expert review also included the assessment of the 'fit' of the conceptual model to the findings from the data analysis. The review resulted in a restructuring of the model to better reflect the study findings. In addition, a proportion of the participants (n =5) in the study were presented with the findings for confirmation that these truly captured their perceptions and experiences (member check). All the five participants validated the findings as truly representative.

Transferability, refers to the applicability of findings to other contexts; similar to generalizability in quantitative research. This is established by using rich, thick descriptions of the data and the data gathering process – detailed interview transcriptions, extensive contextual field notes, and comprehensive demographic information (Cohen and Crabtree, 2006). In chapter four, findings include analytical notes and several sample quotes with the code number of the participant inserted at the end of each quote. Included in Appendix D, are profiles of care provider participants (with no personal identifiers) to help put the quotes in context since they are different types of care providers. Also included in chapters one and four are tables summarizing the demographic characteristics of patient and care provider participants respectively. This is to enable other researchers determine the applicability of the findings to other contexts.

The stability and consistency of data (*dependability*) is demonstrated by the memos describing the processes of code generation, emergence of categories, and theory building as enabled by theoretical sampling. This provides an auditable record of

how the theory was constructed. In this study, memo writing was continuous throughout the coding and analytical process. Some of these analytical notes have been incorporated into Tables 4-2 - 4-9 in chapter four describing the provider perceptions as interpreted from the data analysis.

Confirmability, which is concerned with the degree of neutrality of the data, seeks to establish that the findings are rooted in the experiences and/or perceptions of the participants and not based on the perceptions, preconceptions and/or biases of the researcher. This can be ensured by the previously mentioned periodic peer review and demonstrated by the audit trail established by the memo-writing (Cohen and Crabtree, 2006). In addition to memo-writing in this study, findings from previous research were used to verify the emerging theory (triangulation) and confirm that findings are not clouded by the researcher's perceptions. Also, the researcher's biases were explicitly stated in a reflexivity note; which aim was to 'bracket' the preconceptions and limit their influence on data synthesis and analysis.

Protection of Human Subjects

Data sources

Data were collected from study participants as audio recordings and paper-based forms used for demographic information including race/ethnicity, age category, gender, professional experience and agency employed by. No biological samples such as blood, body fluids, or tissues were collected. All transcripts were de-identified by removing identifying information such as names. However, the audio recordings are considered personal identifiers and steps have been taken to ensure that they are not accessible to non-investigators in this study. In accordance with University of Florida policy, all the audio recordings will be destroyed after the close of the study and all research findings

have been published. These, alongside the transcripts are stored in a password protected and encrypted computer and will be destroyed five years after the close of the study. The paper-based materials do not contain any personal identifiers, but these are also kept locked in a secure cabinet. The raw transcripts are accessible only to the listed study investigators. Again, only persons with certified training in the protection of human subjects and privacy were allowed to view the raw data (full transcripts).

Protection from potential risks

All the research procedures were duly approved by the University of Florida IRB-02 (Behavioral/ non-medical Institutional Review Board) before participant recruitment and other research procedures were started.

Data storage: Care was taken to ensure that all research materials were de-identified. Demographic sheets and transcripts were assigned a unique study number to link the data. The digital audio recordings were obtained with a digital recorder kept securely locked in the researcher's vehicle between venue of each interview and the computer where they were finally stored. Once the recording was transferred to the computer, it was erased from the digital recorder.

Patient and provider confidentiality: As a health care provider, discussion of issues about patients especially persons living with HIV/AIDS without disclosing any personal information was not really a challenge since professional ethics embody patient confidentiality. The challenge was in not mentioning names of other care providers. Participants were cautioned before the interview to refrain from mentioning any names. Efforts were made during the interviews to keep the conversation general and even when specific examples of patients were given, participants were careful to leave out names or simply use pseudo names.

Psychological harm: In anticipation that care providers may feel uncomfortable discussing their experiences with their clients or emotionally stressed remembering care encounters that ended in mortality, eligible participants were informed prior to the interview that they are at liberty to decline participation at any time and were under no obligation to respond to any questions.

Potential benefits to participants

There was no direct benefit to the research participants. However as stakeholders in HIV care, participants experienced a sense of altruism in being able to contribute to efforts aimed at gaining insight into an issue which understanding may result in better health outcomes for this sub-population of their patients. Identifying patient barriers and facilitators and understanding how these influence adherence behavior in this population could potentially inform intervention strategies to enhance medication adherence and consequently HIV-related morbidity and mortality.

Study Significance

To the best of our knowledge, there is no other study that has compared providers' and patients' perspectives on factors influencing care-seeking and medication adherence behaviors specific to African American women living with HIV/AIDS. In addition, no other study has determined their concordance or determined gaps between actual practice and perceived patient needs for this population. It is important that providers are aware of patient-perceived barriers to medication adherence to enable them deliver patient-centered care as well as provide the appropriate tools to patients to overcome their medication-related challenges.

This study will foster better understanding of the medication adherence needs of African American women living with HIV/AIDS and enable health care professionals

(physicians, pharmacists, nurses and case-managers) to provide culturally competent care to the target population and ultimately contribute to eliminating HIV-related health disparities.

Researcher's Reflexivity Note

The objective of the reflexivity note is to minimize personal bias in the study. It involves an introspection of the researcher's previous experiences, assumptions, decisions and choices made that may have any impact in conducting the research (Mruck and Breuer, 2003, p.3).

"My initial interactions with persons living with HIV (PLWHIVs) were through my husband's work. At the time we got married, he (as a program coordinator for Nigerian Youth AIDS Program), had been working with youth populations to educate them on HIV prevention. He later worked as a state coordinator to implement a national comprehensive response to HIV/AIDS strategic plan. All those living with HIV that I met were involved in HIV advocacy activities – they were very knowledgeable about their condition, were gainfully employed and lived relatively healthy lives. My perception of living with HIV was shaped by these interactions. I was trained as a pharmacist, so I had an appreciation of the efficacy of antiretroviral medications. I had come to 'see' having HIV as just another chronic disease condition that anybody could effectively manage and still live a productive life. The only things I considered as barriers were the associated stigma and the high cost of the medication.

In 2009, a few months before I came to start my graduate studies, I had the opportunity to work as a volunteer pharmacist in a rural HIV clinic funded by the United States President's Emergency Plan for AIDS Relief (PEPFAR). The services and medications were free and patients were simply required to enroll in care and come for

follow-up visits and medication refills. As I worked at this care site, I began to observe the loss to follow up and the common late refills. At first I was perplexed - people were being offered free treatment and medications and yet they were not taking advantage of this aid to stay healthy. At first, I was hard on the patients – educating them on the reasons they needed to come for follow up visits as scheduled and more importantly keep up with their prescribed medications. Then I began to listen to them.

From the stories that these patients told me, I began to appreciate them as more than an ID number in a register that I needed to check off as having collected their medications. I listened to them and soon, I started to ‘see’ into their world and understand that there was a larger context to their lives than the HIV they were infected with. There were other dimensions of their lives – social, economic, cultural, etc. – that though unrelated to the HIV infection, significantly impacted their decisions and behaviors related to having the virus. When they told their stories, it was easy to connect the dots and see how various factors interacted to produce these behaviors. A lot had to do with poverty – many had no money for transportation and others had no money even for food. And then there were also structural barriers that were not as obvious. I saw HIV positive women struggling with giving care to a child also infected and the grief of losing a husband to HIV. The stories were varied and yet in some ways similar. I learnt that listening to the patient was fundamental to providing effective care as a health professional.

On starting my graduate studies, I was encouraged to start thinking of my area of focus with respect to research efforts. My experiences and lessons learned had stayed with me. When I saw in literature that here in the US, African American women are the

most disproportionately burdened by HIV, I again thought back to my experiences at the rural HIV clinic. However, I knew that the context of the patients here was in many ways different from the relatively poor resource setting in Nigeria. I volunteered to help out at the Alachua County Health Department and worked with the then HIV bureau to track down PLWHIVs lost to follow up. I kept thinking of the patients I had worked with who I had initially been impatient with, because I did not know why they did not show up at the clinic when they should or take their medications as prescribed. I recalled that the key was listening to them and seeing through their eyes.

I conducted a preliminary study and interviewed ten African American women living with HIV. There were more stories . . . and more insight. But I realized that if these women perceive things in one way and their care providers perceived the same things in a different way, their challenges may not be adequately addressed, hence my interest in comparing the providers' and patients' perspectives. In going into this study I had the following assumptions:

1. Most health care providers who interact with this population are of a different race/ethnicity and therefore may be unable to relate to the context of this population;
2. Providers tend to treat patients using a 'medical model' whereby they think of the patient as a person with a condition who simply needs to take medications with proven efficacy and be well, while patients experience the illness in the context of their lives and the way it affects other areas of living; and
3. Providers view medication adherence more as a patient responsibility than a system responsibility, since medications are typically taken outside the clinic."

Table 3-1. Area 3/13 population profile

Area	Population (2009)	Land area (sq. miles)	Population Density (persons/sq. mile)
Alachua	247,537	874.3	283.1
Bradford	28,512	293.1	97.3
Citrus	146,346	583.8	250.7
Columbia	69,182	797.1	86.8
Dixie	15,649	704.0	22.2
Gilchrist	17,779	348.9	51.0
Hamilton	14,745	514.9	28.6
Lafayette	8,256	542.8	15.2
Lake	305,150	953.2	320.1
Levy	41,293	1,118.4	36.9
Marion	341,870	1,578.9	216.5
Putnam	75,136	721.9	104.1
Sumter	96,422	545.7	176.7
Suwannee	41,086	687.6	59.7
Union	15,860	240.3	66.0
Area 3/13	1,464,805	10,504.9	139.4
Florida	19,021,613	53,926.8	352.7

Source: University of Florida, Bureau of Economic and Business Research, Florida Statistical Abstract, 2008; ESRI Business Solutions, 2009. Prepared by: WellFlorida Council, 2010.

Table 3-2. Refined codes

<ul style="list-style-type: none"> 1. Access to care <ul style="list-style-type: none"> - Availability - Cost - Linkage - Transportation 2. Adherence <ul style="list-style-type: none"> - Clinic visits - Major life event - Medication - Strategies 3. Assessment/Monitoring 4. Care Approach <ul style="list-style-type: none"> - Accommodation - Active listening - Addressing problems/offering solutions - Collaborative effort - Eliciting information - Empathy/sympathy - Goal-setting <ul style="list-style-type: none"> a. Harm-reduction - Holistic - Negotiating - Non-judgmental - Partnership - Patient involvement/ participation - Patient preference - Physical touch - Positive reinforcement - Tailored/individualized - Time/timing - Treating as a person/Respect - Vicarious conditioning 5. Care Expectation 6. Care Outcome 7. Co-morbidities 8. Culture 9. Denial/Acceptance 10. Dependence on care-giver 11. Disclosure 12. Disease/Treatment perception 13. Disparities <ul style="list-style-type: none"> - Prevalence - Vulnerability 14. Domestic violence/Sexual Abuse 	<ul style="list-style-type: none"> 15. Drug resistance 16. Emotional State 17. Fear <ul style="list-style-type: none"> - Being ostracized/abandoned - Disclosure/exposure 18. Healthcare system related <ul style="list-style-type: none"> - Policy - Process - Structure 19. Incarceration 20. Information source 21. Language barrier 22. Legal issues 23. Lifestyle 24. Literacy/education 25. Maturity 26. Mental health 27. Motivation 28. Patient advocacy 29. Patient attitude to care 30. Patient communication 31. Patient counseling 32. Patient education/information 33. Patient involvement 34. Patient knowledge/understanding 35. Patient responsibility/self-management 36. Peer support 37. Pregnancy 38. Provider education 39. Provider-patient relationship <ul style="list-style-type: none"> - Accessibility - Building rapport/a relationship - Building trust - Care and commitment 40. Regimen 41. Religion 42. Shame 43. Side effects 44. Social Support/support 45. Social/Socio-economic context <ul style="list-style-type: none"> - Living conditions/context <ul style="list-style-type: none"> i. Location ii. Social context iii. Stability/ Housing 46. Stigma/Discrimination
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Substance abuse



Figure 3-1. Map of Area 3/13

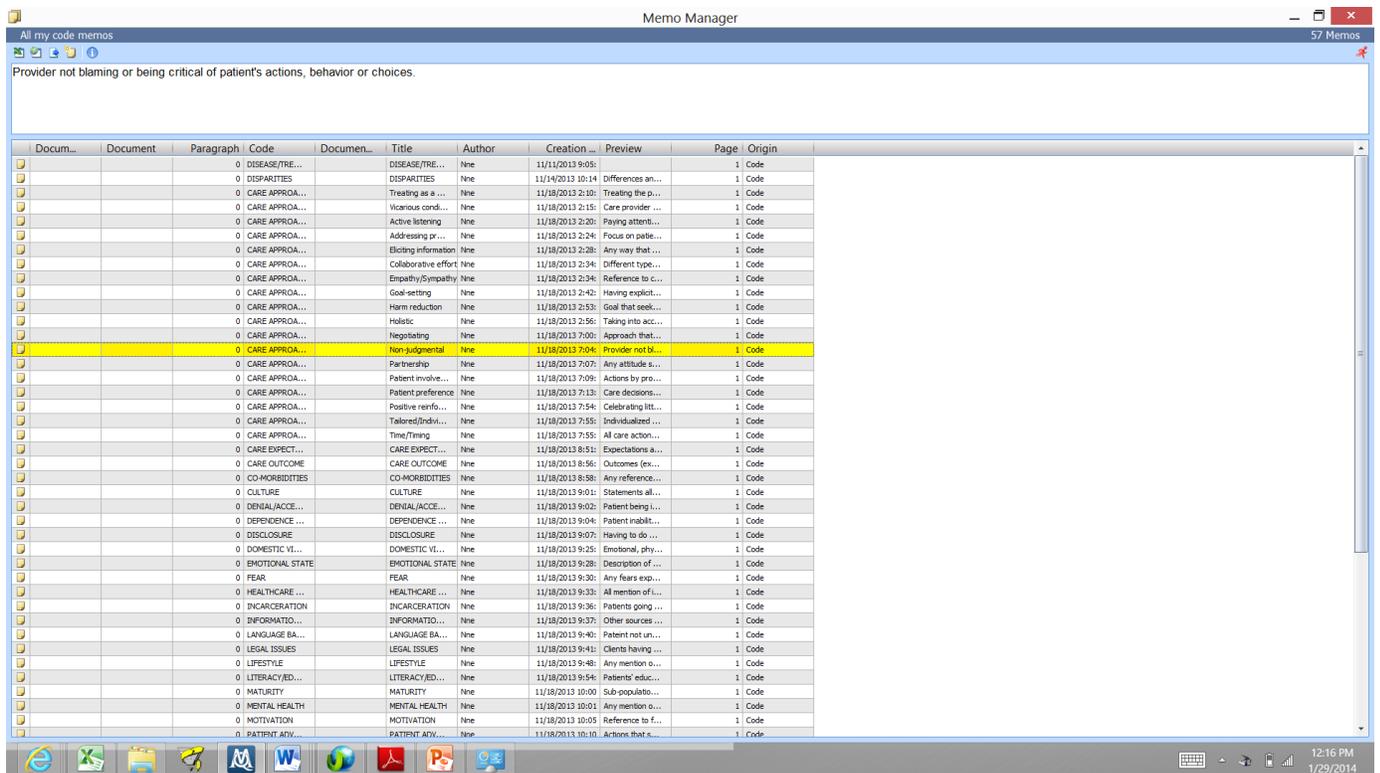


Figure 3-2. Sample memo from MaxQDA 11.0.2

CHAPTER 4 FINDINGS

In this chapter, the findings of the research, based on the stated objectives are reported. This includes the conceptual model generated from data collected during interviews with health care providers working with members of the target population. This is compared to that developed from the preliminary study (based on patient perceptions). Quotes from both providers and patients are provided for comparison and contrasting views synthesized. Providers' views on the gaps between current care practices and the HIV care needs of the target population are also identified from the narratives. Also included in this chapter are providers' recommendations to bridge these gaps.

Demographic Characteristics of Participants

Twenty one interviews were conducted with eight physicians, three pharmacists, three nurses and seven case managers. Fourteen of the participants were female and 16 of them self-identified as Caucasian (Table 4-1). The number of years of experience working with persons living with HIV (PLWHIV) for these participants varied from three to forty (40) years. The average number of PLWHIV seen by each participant per month ranged from less than ten (10) to over a hundred.

Major Categories

From the conceptual coding and thematic analysis of the coded data, eight major categories were identified. These broadly summarize the factors perceived by care providers as influencing care-seeking and/or medication adherence among African American women living with HIV and include the following –

1. Socio-economic context
2. Patient illness experience

3. Mental and emotional health
4. Support
5. Access to care
6. Healthcare system
7. Provider-patient interaction
8. Patient characteristics

For each of these categories, there were sub-categories and themes. These are listed in Tables 4-2 – 4-9. Perceptions of care providers that informed these categories are also summarized in these tables.

Category 1: Socio-Economic Context

Income level, care-giver role and financial responsibility

The socio-economic context of the target population was a major theme recurring throughout the interviews (Table 4-2). A majority of the target population was reportedly in the low income bracket, often unemployed, without insurance and in need of financial aid to access treatment. A common characteristic was the care-giver role that most of these women were said to perform for children as well as older relatives. They were also more likely to be single parents with the financial burden of the home resting on them. As a consequence, providers assessed them as having a lot to contend with and thus treatment for their HIV infection was usually not a top priority (to the patient) considering their challenges of daily living.

Participant: I think that living with HIV, for them, is not like the biggest issue, from what I've noticed. It's maybe the level of poverty that they're into. . . . their income is very low, too. Some of them don't have income. Some of them get food stamps, but a little bit. If they have SSI, then they get only like a hundred. Some of them get just \$80.00 in food stamps. That's like one part of the African-Americans. [*Provider #05*]

Participant: It's not only living with HIV but also everything else that goes with it as far as taking care of the family. Many times, they're the head of the household, which puts a lot more pressure on them. . . . Taking care of the family, taking care of herself. Then they have so many things to juggle

that it's difficult to prioritize what they're going to do. Sometimes they make the wrong decisions. [*Participant #09*]

Instability

Care providers also perceived many of these women as having a lot of instability in their lives. The types of jobs some were able to secure usually entailed working shifts, so that their schedules changed frequently. This constant change was thought to adversely affect medication adherence. Housing was another major issue. Some patients reportedly moved from one location to another for reasons that were mostly financial. For some, living in multiple locations had to do with having a relative watch their children while they went to work. Having stable housing was associated with linkage to and retention in care.

Participant: Consistent housing, living in the same place from month-to-month or year-to-year. A lot of the women that I come in contact with change houses that they live in week-to-week, month-to-month, very frequently changing addresses, with a different person, partner, baby daddy or whatever you wanna call it every other month. Not very many that—that's the majority. There are a few that have a stable—are in a stable relationship, have a stable residence that they're in from month-to-month, year-to-year, but that's not the majority. [*Provider #10*]

For those that needed to re-certify their eligibility for assistance, the paperwork sent to them often went to an address where they were no longer living. Some of them only realized that the deadline had passed when they were unable to get care because they had lost their eligibility. Some forgot their medications in one place when they slept over at some other place, and others (usually the homeless) reportedly had their drugs stolen at times.

Participant: If they're homeless, that creates issues, because the medication could get stolen. Some of the medications can actually be abused by people. They can be ground up and smoked, for instance. [*Provider #02*]

Some patients from the target population had been in and out of jail or prison. While incarcerated, they were adherent to their medication because it was mandatory to visit the dispensary window as scheduled and take the prescribed doses. However, when they came out, some of them did not get into care quickly enough to prevent a 'drug holiday'. Generally, a mobile lifestyle (whatever the underlying reason) was perceived as having a negative impact on medication adherence.

Participant: Another problem with it (*re-determination of eligibility*) is if they're in and out of jail. They're getting their medications when they're in jail. Then, they might come out of jail, but they don't come in for care again for probably months or so. There's lapses in their medication, then . . .
[Participant #10]

Education/literacy level

Educational attainment was perceived as quite low in this population. This was associated with low literacy level thought to affect patients' comprehension of HIV disease, the mechanism of antiretroviral treatment, and even understanding of the instructions and counselling accompanying medication prescription.

Participant: But a lot of times they have very limited education to really understand about the complexities of this infection." [Provider #12]

Lifestyle

Life style issues mentioned included risky sexual behavior associated more with younger women who characteristically had unprotected sex because they naively believed that their partner loved them and was faithful to them.

Participant: And again, we're not trying to be punitive or judgmental. I don't—and I do bring this up because it's important, but I discuss with these young ladies [pregnant and diagnosed with HIV] safe sex practices and the use of condoms because at least the one time they got pregnant they were not using condoms. Some of these young ladies do have a history of multiple sexually transmitted diseases, so I know that at other times they haven't used condoms either. [Provider #12]

Another sub-group that providers talked about was those involved in prostitution or persons who kept multiple sexual partners. Substance abuse was frequently mentioned, but again this was thought to occur in a sub-population of the target group, and was viewed as both a pre-disposing risk factor to acquiring HIV and a barrier to medication adherence.

Participant: Yeah, especially if they have a drug addiction and that's the way they got the HIV, and that's part of the subgroup of the population with the young ladies (*pregnant and diagnosed with HIV.*) . . . It's hard to get them into a program and institutionalize them, essentially, but you can't do it against their will. It's a very, very tough situation, and it's not something other people understand well. It's hard to break that idea. That combination has been very hard for me, for that patient to break through. I don't know. [*Provider #15*]

While some providers acknowledged that a good proportion of their client base was currently or had previously used illicit substances, other care providers said they had few or no drug users.

Participant: I really don't find myself talking too much about substance abuse or pain, asking for narcotics. I don't see that too much. That's something—you just made me think of this with this question, but I don't see that that much. I have other challenges when I'm talking with them. . . . I don't see that much in the African American population as I see in the non—I'm talking about whites and Hispanics. [*Participant #09*]

Domestic violence/ sexual abuse

These women were also reported as tending to go in and out of dysfunctional relationships with some settling for relationships characterized by domestic violence and/or sexual abuse. Many were reportedly living in fear of their partners finding out about their status while others were under threat from their partners to keep their status undisclosed. Abuse was said to be prevalent in this population with occurrences for some starting at childhood and continuing through adulthood. This was thought to be

the underlying cause for mental and emotional instability, resulting in non-adherent behavior.

Participant: With the domestic violence part, I think that and sexual abuse both play into self-worth . . . It's not that—I don't think it's the fact that they've been abused that makes them not adherent. I think it's the fact that they've been abused and they have all this mental trauma and decreased self-esteem that makes them not adherent . . . in my experience—any female patient needs to be—any female patient, I don't care what color they are, need to be screened for domestic violence and for being abused sexually, but especially in the population you're—I think it's rampant. [*Provider #02*]

Life-changing traumatic event

There were narratives of patients who had been adherent to taking their medication, but suddenly started 'falling off the wagon'. On probing, care providers said they discovered that there usually was a life-changing event (like the death of a loved one) that had occurred to change the patient's adherence behavior.

Participant: I've had one lady come in recently and she's always been pretty—she's a pretty smart lady. She got it. She was taking her medicines. All of a sudden, she had this blip. It's like, "What's going on here?" She told me her brother died . . . She had a crisis. Yeah. "Let's try to get you back on the bandwagon here." I understand it. It happens. Sometimes you can't be perfect forever and these things do happen. Just try to be supportive for her and get her back on track. Maybe keep a little bit closer eye on her in the future. Instead of seeing her maybe every four months, see her every two months for a while or do her labs a little bit more frequently. [*Participant #16*]

Generally, disparities in HIV-related care and health outcomes [for women in the rural areas] were perceived as being more significantly associated with socio-economic status (SES) - income level and education as proxy; with race/ethnicity as a possible confounding variable. In other words, women in the lower socio-economic stratum generally were seen to experience similar issues with accessing care and medication adherence irrespective of their race/ethnicity

Participant: They're (*referring to African American women*) just like women everywhere. It doesn't matter the color. I think that in rural areas, sometimes those racial disparities aren't as apparent in my experience. It seems like the economic situation's very similar. The education level tends to be very similar among all of my women, white or black. [Provider #03]

A summary of themes and participants' perceptions regarding patients' socio-economic context as it relates to medication adherence is provided in Table 4-2.

Category 2: Patient Illness Experience

In this population, care providers perceived patients' personal experience in dealing and living with HIV following their diagnosis as having considerable influence on their adherence behavior. The different phases in the illness experience are thought to either hinder or enhance medication adherence (Table 4-3).

Denial

Patients commonly experienced denial at diagnosis, and for that period were unlikely to engage in care. However, some patients reportedly also went into denial following treatment (when symptoms were no longer experienced or viral load was undetectable). Some providers alluded to having patients who were adherent to their medication but were purportedly still in denial.

Participant: Yeah, I'm saying that most of my Afro-American clients fall into a level two or three (*referring to severity category*), and the reason being is number one, if they're newly diagnosed or have been diagnosed within a year or two, they may be in denial, okay . . . the majority of 'em have—they could be in denial. They say, "Oh, I feel fine. I don't need meds. I don't have that". [Provider #01]

Participant: Then you have a group of patients who don't take 'em because after they start taking them they feel better. That's when maybe a little denial kicks in, if you know what I mean. [Provider #16]

Acceptance of HIV status

Acceptance of HIV status was reported as usually occurring with increased knowledge and understanding of HIV disease and the mechanisms of the antiretroviral treatment. For some members of the target group, acceptance was based on an assurance drawn from their faith in God.

Participant: ***[By the time they come to you where are they at? Are they usually where they have accepted it . . . ?]*** For most of them - yes. I've heard a lot of them say, "It's in God's hands. Everything happens for a reason. All I can do is go see the doctor, be on medication, do what I gotta do to make this better. . . . Most of the time they've accepted, or are at least on the road to accepting, and they just want help. There are still, like I said, a handful of people that will just sit here and cry. They'll file the paperwork, and just cry. Any time you mention the phrase HIV, they just cry."
[Provider #08; case manager]

Perceived control of HIV disease

The physicians reported that often times when patients experienced improved health outcomes and saw a significant change in their clinical values following treatment they tended to gain a sense of control. Acceptance of HIV status usually preceded perceived control.

Participant: Number one, they wanna live, okay? A lot of 'em have children and they want to see their children grow up, so they're living for somebody, okay? They do say they live for themselves, but they understand now that this disease isn't going to kill them, that they have control over the disease. If they can learn that they can control the disease and not let the disease control them ***[What gets them to that point of understanding and perceived control of the disease?]*** They start feeling the effects of the drugs. The drugs are affecting how they're feeling. They've got more energy. They're eating better. Once the drug is working for them and their viral load goes down, and they're not succumbing to other diseases, or infections, or what have you, then they go, "Hey, it is doing somethin' for me." The light bulb comes on and they realize that, "Okay, it's not as bad as I thought it was gonna be." That helps. [Provider #01]

However, the narratives also suggested that a sub-set of patients from this population while not surprised at their diagnosis of HIV (based on their risky lifestyle)

are neither accepting of their status, nor necessarily perceive themselves as being in control of the disease.

Participant: It's part of the life they've lived. They almost expect it, there are—because of their way—their relationships, different partners, or they were prostitutes or they're drug prostitutes. It's almost like, "Whatever." I've had very few come through that are really shocked and surprised, but a lot of 'em just—it's like another day . . . I don't know that they accept it. I think it's just there. Almost like they expected that it might happen, but they didn't do anything to prevent it from happening. I don't know that they truly accept it. **[Would you say they are really not in control of it?]** Definitely [Provider #10]

With acceptance of their HIV status (and in some cases 'perceived control of HIV disease), patients were reportedly more likely to disclose their HIV status and consequently received the much needed social support. With available social support, providers also reported the likelihood of better adherence levels.

Participant: We talk about who knows about the diagnosis in their family or their household where they live. We talk about who supports them—who's gonna support them . . . We talk about that also and we're looking for them to have somebody who's a support who's gonna help them get through this. . . . Really knowing also that we, the doctor or the nurse—the professionals—we can't be the same kind of support that everyone needs, which is more of family and friends. . . . Yes, they do (better adherence with social support) in terms of being able to stick to the regimen. [Provider #17]

Self-disclosure of HIV status

As part of the process of care, providers said that they usually encouraged patients to disclose their HIV status to someone they could trust. The goal was to ensure that the patient had some support at home. From their narratives, those who finally disclosed to a family member(s) usually received the much needed social support which providers reported as enhancing medication adherence. They reported that some patients had family members come to the clinic with them. Those accompanying the patient often helped in reinforcing the information they received as well as reminding the

patient to take their medication. However, providers generally stated that members of this population were not always willing to disclose their status to family members, especially following their diagnosis, as they feared being isolated or losing the family relationships they had.

Participant: Because of the stigma, some of them, they isolate. They don't disclose their status to relatives, mother, father, sometimes the spouse, children . . . That's another thing that they're living with that they're hiding. They don't feel comfortable disclosing that to their family for fear of isolation, rejection and other tragedies. They can lose a family because of the misconception of people having HIV . . . people jump to conclusions. [Provider #09]

Drawing from their experiences, some of the providers interviewed reported that most of the patients did eventually disclose their status to a family member(s) after some time had passed. The time span between diagnosis and self-disclosure was reportedly variable from one person to another.

Participant: Eventually, though, they do make that effort and tell them (*reference to family members*), and then they have good social support. . . . Over the years, they've told them, and then finally they have come to terms with it. [Provider #19]

Older women were reportedly less likely to disclose their status to family members compared to younger women. They (older women) were also described as having better coping skills.

Participant: They (older women; not pregnant) don't, they generally don't want anyone in their family to know, so they're dealing with it on their own. . . . The younger women don't seem as intent upon, "Oh, this has to be kept absolutely confidential." As a matter of fact, I've never had a single one say that to me. I've said, "Oh, does your mom know? Does your—I mean, who are people around with you, who can we talk about this in front of," [Provider #12]

Motivation

A key factor identified by providers was having some motivation to take their antiretroviral medication. As part of their care approach, providers engaged patients in dialogue to understand their context and determine important aspects of their lives that could serve as motivation. Hence part of the care process was to get patients to a point where they were motivated to follow through with self-management and making the required follow-up clinic visits. Different factors and various aspects of patients' lives were identified as potential motivators of medication adherence. These varied from patient to patient and included their care giving role, living to see their children grow up, prospects of maintaining a simple regimen, perceived efficacy of the treatment, a spiritual encounter or a near death experience.

Participant: You've got to find—and every patient's different. For some people, it might be children. For somebody else, it might be a parent that's sick and needs their help. You need to be there for your mom. I know she's not doing well. She's got Alzheimer's. She's gonna need you there. You've gotta figure out what it is. It might be love for somebody. They're in a new relationship. You've gotta try to figure out what motivates that person, and how can I use that motivation in a positive fashion, to get them to be adherent. You have to have a reason. [Provider #02]

Category 3: Mental and Emotional Health

Patients' mental and emotional state was reported as a significant factor in their ability to follow through with self-management of their HIV treatment. This factor was repeatedly brought up as a major barrier to medication adherence in the target population.

Psychiatric disorders

Some providers assessed many patients' in this population to have pre-existing mental health issues and depression prior to HIV diagnosis. These, they reported, were often untreated because of the associated stigma.

Participant: Mental illness is a big problem in these ladies. . . . Sometimes it is (ref: mental illness associated with HIV). Usually it's not. Usually it's like bipolar disorder. The ladies that I've had that've really had a hard time recently have had bipolar disorder, and they just refuse to go back to the psychiatrist. . . . We kinda struggle with that because some of them have significant enough psychiatric disease that I do not feel qualified to be the person deciding that side of their care. They have access to mental health providers, but they don't wanna go. [Provider #03]

Depression

According to the participants, other psychiatric problems were associated with the HIV diagnosis. HIV-related depression was a common feature among patients because of their perception of the disease and the stigma associated with having the infection.

Participant: We see quite a bit of depression. Adjustment disorder is quite frequent, even more in the first stages of the HIV. Everything just falls apart. As I mentioned before, the stigma of "What's gonna happen with my family?" Just carrying a diagnosis of HIV, that has to be very depressing. I would say depression is the most common mental problem that I see. Of course, in the community, we have very limited resources to treat this condition. That falls onto us a lot of times. [Provider #09]

Emotional distress

Participants reported that a lot of emotional distress was brought on the patients by their feeling of anxiety concerning the outcome of the disease especially following diagnosis when HIV knowledge was usually low. In some cases where the person had indulged in risky sexual behavior, there were feelings of guilt and self-condemnation.

Even some of the older women who reportedly contracted the infection from their husbands or significant other were said to feel some sense of shame.

Participant: I think that shame's a big issue. I think that they see themselves as having made bad choices, and they judge themselves that they've made these bad choices. That's a big thing that we talk about. You don't know what your partner's doing. You don't know where they've come from . . . When they come and I can— . . . I'll say a lotta people that have been diagnosed with HIV have a lot of shame about their diagnosis. [Provider #03]

Instability

For those who had not disclosed their status, they lived under the constant fear that someone might find out about their status. Those in relationships or living with family members were often afraid that someone would discover their medications and result in their being abandoned or ostracized. They also feared experiencing stigma and/or discrimination in their immediate community or in a public place because of their status.

Participant: I see a lot of—from the African American perspective, there's a fear initially about telling the family or any social supporter—their significant other—about telling them about the diagnosis . . . initially, I've seen that hesitation, probably with all of them, but it seems like it's more with African American females cuz there are a few that even their children don't know. Over the years, they've told them, and then finally they have come to terms with it. Otherwise, that fear is there. [Provider #19]

These negative emotions were cited as affecting patients' general well-being and influencing the way they responded to their prescribed regimen. For example, some patients would skip doses if there was a chance that someone might see their pills and ask questions. The constant heightened state of fear contributed to their distress and impacted their adherence behavior.

Participant: Fearful, in terms of they're the only person that knows that they have HIV. They're not telling anybody else. They may not tell their spouse. They may not tell their family members. I think that they're very fearful about

seeking care for that reason. They're afraid that the secret will get out somehow. I think that's a big barrier. A lot of them are fearful. [Provider 02]

Participants' perceptions on how mental and emotional health affects medication adherence in this population are summarized in Table 4-4.

Category 4: Support

Having support was acknowledged by most providers as being crucial to successful treatment of HIV. Various forms of support were described.

Social support

Most of the care providers interviewed said they always encouraged patients to find someone they felt comfortable disclosing their status to with the objective of having some support. Those who had some support from family members were found to do better in terms of medication adherence.

Participant: I think a family support is something that they already have, so that's actually positive, that actually, so I think a big—you know, having a good social support at home, maybe strongly I'm looking at that, because that's your first safety net, honestly, even before your physician. [Provider #14]

The lack of social support in a sub-group of this population was attributed to the unavailability of persons to provide instrumental support such as childcare. But for the most part, the lack of social support was said to be as a result of non-disclosure of HIV status by patients in the target population due to the associated stigma.

Participant: I think that there are issues with social support that may be more of an issue for African-American ladies. It seems that sometimes they have to be a little more independent, particularly when they have children. A lotta times, they don't have somebody to watch their kids, and they'll bring their kids to the clinic. That is something that I notice a little bit more, that they are tending to be a little bit more independent, [Provider #03]

Care providers also acknowledged the importance of the spiritual dimension characteristic of the target population and role of the church in providing emotional

support. They suggested that patients who trusted in God and believed in His divine ability to sustain them probably fared better with their medications and illness in general.

Participant: I would say that those who are very religious and they are more devoted to religion probably they do a little better. Of course, they pray. They have different things; they can focus their attention on other things besides not doing what they're supposed to be doing. Probably, I really cannot tell you based on experience if they do any better than others. Just thinking of it, maybe they do a little better if they are more engaged into their religion, whatever they prefer to pray to. [Provider #09]

Instrumental support

Another form of support was the type that directly facilitated care and included strategies to aid medication adherence such as pill boxes and alerts to remind patients to take their doses. For those in more rural areas, there were pharmacy mail order services designed to ensure timely refills by getting their medications to them rather than have them come into town to pick them up.

Participant: It does help and it's thankful we have those—access to those mail-order pharmacies and the pharmacies that will pack everything up for 'em in a pill box. If they come see me and they've got all of their medications and like I've offered them plenty of pill boxes before and I'll set it up for them. There's one patient I had set up for two weeks for them before so they'll know how to do it the following two weeks.[Provider #18]

Supportive services that addressed patients' non-medical needs (such as transportation, housing) were also identified as alleviating patients' competing problems and thus helping them focus on taking their medications. In addition, services such as mental health counseling, case management and payment for their antiretroviral medications were also reported as facilitating care and enabling in medication adherence behavior.

Participant: If they have a safe place to live, and they have their lights on, they are more inclined to go to the health department because they're not worrying about, "Where am I gonna sleep tonight? Where am I gonna eat? Where am I gonna get my dinner? How am I gonna keep my medications

refrigerated, if they need to be refrigerator?” or “How can I keep my meds from being stolen from me if I’m homeless?” Because people will rob the homeless quicker than they’ll rob anybody else. I think it improves their odds of going and maintaining. Cuz it takes that level of worry off. Then they can focus more on their healthcare. Cuz they’re not stressed about paying the rent, where am I gonna sleep tonight. [Participant #06 – *on providing support for housing through HOPWA – Housing opportunity for people living with HIV/AIDS*]

Peer support

Peer support was perceived as having potential to provide the kind of support that family or care providers were unable to give since they did not have the virus. Having someone who actually had the disease and had effectively been maintained on ART help the newly diagnosed navigate the care process was considered a helpful strategy. Many of the providers interviewed did not have any empirical evidence of the direct benefits to medication adherence in their patients. There were speculations that patients would likely be more receptive to medication adherence counseling from persons living with HIV as people who could identify with their illness experience.

Participant: Going to these support groups I think is helpful. To talk with somebody who just went through this not too long ago, and is understanding. Sometimes it’s hard to talk to somebody that doesn’t know. You can tell me all about the side effects to your medication, and I can say, “Oh that sounds awful.” I have no idea . . . If they go to a support group and talk to somebody else, they could be like, “Oh thank God you didn’t have this, cuz I used to have that.” They can kind of help each other out. I’m not exactly sure what goes on in the support groups, cuz it’s just for positives. It’s all about empowering, and uplifting, and helping them get through it. ” [Provider #08]

Some providers had only recently become aware that peers were being involved in HIV care to enhance health outcomes. Participants, however, acknowledged that some of their more adherent patients were active members of HIV support groups, and suggested that the support received from such affiliation was somewhat instrumental to improved adherence and well-being in general.

Participant: I just found out in another conference that there are peers who have HIV—volunteers who are willing to talk, and I think we have to make more use of them. I didn't even know that – [Provider #19]

A summary of provider perceptions about support to patients in the target population and how this influences medication adherence is provided in Table 4-5.

Category 5: Access to Care

Availability of relevant services/ resources

Another major category identified from the analysis of the data was patients' access to care. Consequent to their socio-economic status (SES), a significant proportion of the target population were reportedly living in more rural areas with fewer care facilities and services available to them compared to the more urban areas.

Participant: I feel a little anxiety for my ladies because if they lived in Fort Lauderdale, or West Palm, or Miami, or Tampa, they would have access to so much more. Here (rural) they're very limited. We don't have a lot of funding. [Provider #13]

In some cases, even where some relevant services were readily available (e.g. mental health counseling), some patients were unwilling to access those because of the associated stigma. Hence, some of these were under-utilized.

Participant: That is something that our program pays for. We do have—the Ryan White Program has mental health counselors. It is super, super underused. Not very many of our clients access it. We have a really great case manager who has a background in psychology, so she's really trying to push that on a lot of the clients, trying to erase that stigma of, "You're not crazy just because you go talk to a counselor." I think that's one of the main reasons why a lot of the people don't access that services is because the stigma behind . . . [Participant #10]

Affordability of healthcare services

As a result of their SES, insurance coverage for many women in the target population was minimal or non-existent. Even with financial aid, some services such as mental health were in some cases not covered. Financial aid where available was also

subject to eligibility requirements that were not entirely discriminatory in identifying persons in need. For example, in calculating income, all house-hold residents' income was included irrespective of whether they provided financial support for the client or not. These access issues were identified as possible barriers to linkage to care and ability of patients to maintain follow-up visits. In contrast, various assistantship programs were also mentioned as being currently or previously in place to help patients who were financially incapacitated with their medical bills and medications.

Participant: The ADAP program's gotten a little bit restrictive about managing some things. For instance, one thing that's happened over the last couple of years—we talked earlier about mental illness and depression being part of HIV care a lotta times in this population. A year or two ago, the ADAP program, because of budget cuts, stopped paying for antidepressants. They were covering some antidepressants, and they stopped. That made my life a lot more difficult, in terms of taking care of my patients, because a lotta them really benefited from the antidepressants. Then when the antidepressants were stopped, didn't wanna be as adherent. That was a problem. You try to find things on the four-dollar formulary that they might be able to afford, and you try to get around it, but still, that made it more difficult. There's been advances and declines in the way that the drug assistance programs worked over the last few years. [Provider #02]

Accessibility of health care facilities

In some of the counties within the area of interest (Area 3/13), persons living with HIV had to access care in another county and many of these people had no car and the area had no public transport. Getting to the clinic was therefore a major challenge.

Those who were eligible for Medicaid van or the Social Security vehicle were still faced with the challenge of scheduling for the vehicle in advance (as required). Some vehicles were scheduled to pick up multiple clients so that patients had long waiting times. Even where these forms of transport were available, some patients reportedly preferred not to utilize these services because of the associated stigma.

Participant: There are services available in some areas, but they have to have transportation to get there, and transportation is probably the biggest problem. There's no public transportation. If they have Medicaid and they are functional enough to make their appointments three days in advance— . . . but that (Medicaid transport) takes being functional, having a phone that has minutes on it. It takes a lot of effort on their part, and so sometimes they have to pick where their effort's gonna go. For us, it's not a big deal. We have vehicles or we live in a town where we can just ride the bus, but for them, it's really hard. *[Provider #03]*

Some others were not aware that these services were available. There were also those who had readily available transportation any yet did not make it to the clinic for their scheduled visits.

Participant: Part of the time they said it was transportation difficulties, which I could believe knowing where they lived and how far they'd have to go to get to the health department. We pointed out, we'd get arranged transportation. They would go sort of sporadically. I just don't understand why you wouldn't wanna take care of yourself if you're pregnant, but they didn't. *[Provider #06 – attributable to other factors]*

Category 6: Healthcare System

There were a number of care processes and structural factors within the health care system that were identified by care providers as having some impact on how patients in the target population obtain care and their ability to stay on their prescribed regimen.

Complexity of and inefficiencies in the care process

Excessive paperwork: As a consequence of the prevalent low socio-economic status in this population, the care process for most newly diagnosed African American women was reportedly initiated with an assessment of their eligibility to receive financial assistance. This assistance was to enable them obtain anti-retroviral treatment and other supportive services such as counseling and augmentation of rent for housing. The volume of paperwork involved for the eligibility process was perceived by care providers

as excessive (and therefore a deterrent to care), considering the literacy level of most of these women. In addition to the initial eligibility assessment, clients enrolled for assistance were required to re-certify their eligibility status every six months in order to continue receiving treatment. The re-certification also involved more paperwork. Even though a reminder was sent a month prior to the deadline, clients were said to struggle with keeping up with the process usually because they had other competing problems.

Participant: It slows the process down in my opinion. . . . I don't see where adding an extra layer of unnecessary paperwork to people who are already overburdened and many of them are illiterate, or not very literate, and don't understand forms, and stuff, is improving their quality of services, or is improving their getting any healthcare. I don't see it. That's the one thing I'd change. I'd cut that out. *[Provider #06]*

Restrictive policies: The inefficiency of the health care system in meeting patients' needs was associated with policies that care providers perceived as more restrictive than enabling. A policy related problem was the structure of the insurance and how billing was coordinated. Some patients reportedly could not get refills even when they ran out of their medications until the next billing cycle had started. Hence, there was a 'forced' drug holiday. Policies also placed restrictions on replacing medications that were lost or stolen, such that a patient whose medicines were stolen (a circumstance that was not uncommon given the housing situation of some clients) often had to wait till the next refill to continue with their medication.

Participant: I think that at the state level, I think we're spending way too much time making people jump through hoops to get their medicine or to do this or that. I think it's affecting them being able to take their medicine. I think it's affecting their attitude about how we take care of them and all of that and I think it just creates problems right and left. I mean that certainly is something that I would be—if you wanna talk about policy or implementation of policy, in fact, probably is better phraseology. I don't mind the general idea of, "No, you gotta be seein' the doctor and gettin' your lab tests and followin' through to keep getting your ADAP medicine or to make sure you still have your Medicaid." I don't have a problem with

that. It's this cutting off of medication because they missed or they didn't meet the deadline (*reference to re-certification of eligibility every 6 months*).[*Participant 17*]

With regards to enrolment in care, those preferring to seek care in the infectious diseases unit of the academic health care setting rather than the health department were put on a waiting list. Though providers did say that priority was usually given to persons diagnosed with HIV, it still implied a waiting period that could delay initiation of treatment. In addition, patients enrolled in care in the academic health care setting were required to meet certain requirements in terms of keeping up with their clinic visits or else they would not be retained as patients.

Participant: ***[Do you have a waiting list?]*** Yes, I think that does become an issue. That is an issue. I think it's just like justice delayed. Even if you're doing a great job, if they're not able to get in, that's an issue and that's not being addressed correctly. One of the providers who's been working out in communities having the clinic here or any things like that, so it's an issue we're cognizant of. We usually find a way to squeeze, especially our HIV patients, in cuz there, it's a time-bound thing. If you can leave out someone, we do, but if we have the time. My sense is that we're able to get them in quite quickly cuz we understand the time delay at this point in their care, really try to . . . We do see them. [Provider #15]

Of particular concern was the way referrals were made especially for mental health treatment. Patients could only be given contact information for where to seek help; leaving it up to them to initiate the contact and actually obtain the treatment. Mental health issues when left untreated were said to adversely affect adherence behavior. Many of the patients referred reportedly did not follow up with the contact information given.

Participant: They're referred. We give them the confirmation. The doctor gives them contact information. Sometimes the doctors' offices will call, but we try and encourage the clients to take responsibility for their care. A lot of 'em go, others don't go. . . . We can help, but the facilities require the patient to call. The majority of the facilities do because they want the patient to take the first step . . . [Provider #01]

Fragmentation of the healthcare system

Coordination of care: Care providers attributed part of the adherence problem to the fragmentation of the healthcare system. Patients in the target population often received care in more than one care setting usually because they had co-existing conditions or had minimal or no insurance. While some had case managers that helped co-ordinate their care, others had to meet up with the different appointments.

Integration of patient health information: Again, since the different health problems required treatment, the ideal would be that each care provider be aware of the prescribed regimen from other attending providers. This however was not always feasible because not all the facilities were equipped to input or access patient electronic health records. Drug reactions resulting from con-current administration of contra-indicated medicines were perceived as a likely reason for stopping ART.

Participant: Part of it is a fragmented system, as well. They're dealing with the county department or with another provider and having to come here. I think there are a mixture of issues. . . . I think as much as we value privacy with HIV, it can work against them. It's much more difficult to get their records, and their labs, and what they've had done before, and so on. Being Florida, they might've moved from a different state and so on and moved here and things like that. The fragmentation is the worst part. People get hospitalized at different facilities and especially with HIV-related information, it's not transferred as easily and people forget. The fragmentation in general is bad with the healthcare system, but it's especially bad with HIV. [*Provider #15*]

Characteristics of the care setting

In terms of the care setting, privacy was identified as a major issue. Clinics structured such that the waiting area or the entrance to see the physician in any way indicated that patients were there to seek HIV care were unlikely to encourage patient adherence to follow-up visits.

Participant: The only other issue that I've heard people mention, and this is specific to *[mentions a county]* - is that with the layout of the *[mentions county]* County Health Department some of them feel uncomfortable going there because the waiting room is a general room. Then when they call you back to the specialty clinics everybody knows where you're going and why. I've had several clients tell me that's why they won't go there. They go to another health department. *[Provider #06]*

In care settings (like the academic hospital), physicians were rotated and patients were unlikely to see that same provider at each clinic visit. This was also reported by some providers as being a barrier in building effective provider-patient relationship needed to achieve successful treatment in this population. Providers from the academic setting however reported that their aim was usually to build a relationship with the patient as a team, while still allowing patients see their preferred physician when possible. Other possible deterrents to care in this population as cited by the participants was the long waiting times at the clinic and patient dissatisfaction with the face-time with the care provider.

Participant: The other thing that is important when you're trying to reach out to people, I think, is they need to get to know you and know that you're there for them. One of the problems that some HIV clinics have is they're rotating providers in and out all the time. I think that that's really difficult to do with this population. It's much easier to do it for a more educated population than one that is really in difficult circumstance. *[Provider #02 – consistency of care provider]*

Resources

The lack of resources to provide supportive services such as housing, transportation and especially mental health counseling had frequent mention in the participants' narratives. Some providers also thought that while funding was limited, that available was not being utilized in the areas of priority such as mental health treatment.

Participant: See, the problem here in this country, I feel—I'm not tryin' to be political here—is that it doesn't have to do with the resources. It's the allocation of the resources. Here, I think the problem that they have is there's two

services that HIV patients don't have enough of. One of 'em is psychiatry and one of them is nutrition. [*Provider #1 1*]

Category 7: Provider-Patient Interaction

Under this category, three major themes were identified— the patient-provider relationship; the provider's approach in delivering care to this population; and the mode of communication adopted in interacting with patients.

The provider-patient relationship

Key aspects of the relationship that providers perceived as important to patients were being accessible to patients (which was usually accomplished by providing patient with a personal telephone number at which the care provider could be readily reached); having a personal knowledge of the patient; and taking out time to build rapport and trust. The element most emphasized by care providers however was a demonstration of care and commitment to patient's treatment and well-being. This was perceived as key in enhancing patient adherence to follow-up visits and taking their medications.

Participant: They have to know that you care about them. If you can do nothing else that first visit, if they leave there thinking, "You know, I kinda like that guy," or gal, you have made a start. If you don't—if they do not understand that you care for them and you really want the best for them, they're not gonna do what you ask 'em to do. If you can get that across to them over the first few visits, that is what I think you need. That's the foundation that I try to work on. The old trite phrase that's used sometimes is, "They don't care how much you know until they know how much you care . . . They have to believe that you really want to help them." [*Provider #02*]

Provider's care approach

With regards to the care approach, care that was patient-centered rather than disease focused was reported as producing better treatment results. A patient-centered approach as described by participants include taking patient preferences into consideration; inclusion of patients in decision-making; encouraging patient participation

in care and generally aligning treatment with individual 's specific context and challenges. Providers also recognized that negotiating with patients on treatment choices resulted in better adherence than prescribing treatments without duly consulting with the patient. Other approaches that providers talked about included investing time to understand the patient's context; collaborating with other care providers to give comprehensive care; positively re-enforcing little successes (like making it to the clinic) and setting incremental goals that patients felt more confident achieving (for example reducing alcohol intake versus abstaining). Other important care approaches included talking to patients about other persons successfully managed on ART as well as addressing patients' medication-related problems (eg. side-effects) with effective solutions. These built confidence in the provider's competence as well encouraged patients in continuing their treatment.

Participant: HIV practice right now, it's just more than medicine, quite honestly, because that is a stigma attached to it, like you don't want to come across as a medical healthcare provider. You want to actually be coming across like a sort of a holistic one where you're ready to help them through whatever issues they're dealing with at home, and then, you know, and yes, inserting the HIV care into it. [Provider #14 -*holistic*]

Participant: Being more willing to change the normal—normally, I would be, "You can't leave unlabeled things around. You gotta be specific about your storage and how you handle things. I don't want you to have access to that in the car with a child." . . . I agree, but "I also want you to live as long as you possibly can and have the best life that you want, so we're gonna make an exception, and we're gonna do it however it works for you." That's the biggest thing I find for women, I think, in all things— [Provider #20 – *tailored/individualized; patient-centered*]

Participant: We do give you the choice of seeing someone or not seeing someone because you might like me and like two other people, but you might not like the fourth person or whoever it is. . . . There are some patients who specifically ask not to see one of us, and we completely honor that.[Provider #15 – *preference; patient-centered*]

- Participant: I can tell them the reason medically, what I think about their CD4 counts or their viral load or what I think could happen if we delay treatment longer. These are the things that I'm looking for to say, "Emmm, it's time to start medication," right? "I don't think we should wait and here's why we shouldn't wait." With that, that little bit longer—but they need to be part of the decision. It can't just be me comin' and goin', "Ya hafta' do this." [Provider #17 – *participation; patient-centered*]
- Participant: Yeah. "Why is it that you don't wanna do it?" Being honest and making it very clear, "I'm gonna try to find another way? What is it about this way that you don't like? What is it about this drug that doesn't make it happen?" rather than just watching someone decline and then yelling at them about it cuz I think that a lot of times women—if it doesn't work out, they just don't do it. [Provider #20 – *motivational interviewing*]
- Participant: That was kind of like getting to know them. I would really try to spend a lot of time with the patients at that point (initial encounter), depending on what their level of illness was . . . It's just spending time with them and trying to explain things to them and not trying to rush them. I know myself, when I feel like I'm rushed out of the doctor's office, I don't like that. [Provider #16 – *time investment*]
- Participant: I look for moderation. I don't tell 'em to quit drinking. If I can get it down to a moderate level, then I might be content with that. [Provider #02 – *goal-setting; harm reduction*]
- Participant: Obviously, when it comes to adherence and it comes to stabilizin' somebody after their diagnosis, it's not just one person. It has to be a whole multidisciplinary effort. [Provider #11 – *collaborative effort*]
- Participant: I usually walk through a comparison with another patient of mine without a name, someone out there who has gone through this and that right now, this is where we are and this is what we do. That seems more understanding . . . Telling them that, "Someone in your shoes was here a few months ago and that we went through the same process and now, they're at a better place. In very many ways, you're very similar to her, and that we walked together along the same path, and you and I can walk along the same path that we've walked before." If you want to call it a strategy that I use. [Provider #15 – *vicarious conditioning*]
- Participant: they were a month taking their medicines before they quit. They were two months taking their medicines before they quit. You gotta look at the, "Oh, great. You came to all your doctor's appointments." You know, those little carrots of positive reinforcement that you could do you know? Well, it's critical. "You made it to this appointment. Great. You picked up your medications at the same time three months in a row. Great. Your CD4—your viral load—are doing what they're supposed to do. Eureka!" You

know? I mean so it really has to be a lot of positive reinforcement. Yeah, yeah. [Provider #13 – *positive re-enforcement*]

Participant: That was one of the big things that I thought they did really well with [chain pharmacy employed in]. They were really big about the culture and the person. You're treating a person. You're not treating a number, and you're not treating a med. [Provider #20 - *Treating patient as a person (Physical touch, Respect)*]

Provider-patient communication

How providers communicated with patients was cited as very important in the care process. Communication in a non-judgmental manner was emphasized. Providers talked about how active listening in patient communication was pivotal to understanding their needs. This enabled providers to obtain information pertinent to delivery of competent care.

Participant: They know that our clinics are a no-judgment clinic. I try not to make it a situation where there's any judgment. When we talk about risk factors, I try to have no judgment I say things like, "I am not in your shoes. I don't know what decisions I would make had I been in your shoes. Don't ever feel like I'm judging you about anything. . . [Participant #03 – *non-judgmental*]

A good provider-patient relationship was perceived as significantly enhance adherence in the target population. A summary of participants' perceptions on the influence of specific characteristics of the provider-patient interaction and relationship on patients' adherence behavior is provided in Table 4-8.

Category 8: Patient Characteristics

In addition to the patient's illness experience, specific patient characteristics were perceived by providers as affecting medication adherence in this population.

Patient knowledge and understanding

Different care providers confirmed that HIV knowledge was usually low at the time of diagnosis. Providers reported that as patients were educated and counseled

over time, knowledge increased with resultant change in patient perceptions. However, patient's ability to cognitively process information was important. Some patients were assessed as unable to comprehend information being given to them despite repeated education and counseling.

Participant: If they can understand what the numbers are and why they're taking it, I think that helps. That goes a long way . . . Knowledge is power certainly. I think the more patients understand, the better it's gonna be. Some patients, you can tell from the get go that they get it. They get it – 'I've gotta take these medicines. If I don't take these medicines' —other patients never get it. There's some patients you just have to realize at a certain point it's a cognitive issue. It's a cognitive issue. No matter what you do, they don't get it." [Provider #16]

In contrast, there were patients who were assessed as being knowledgeable about HIV, yet remained non-adherent to their medication; suggesting other attributable causes.

Participant: I have some ladies that seem like they are so knowledgeable, that they're motivated. They'll text me; I'll text them. They'll come and their viral load's half a million because they're not taking their meds. It's a very strange thing. [Provider #03]

Patient disease/ treatment perception

Providers interviewed reported that patients' perceptions of the disease and ART at the time of diagnosis was mostly shaped by normative beliefs and oftentimes augmented by invalid information from non-medical sources such as relatives. The providers said they had the task of educating patients to change these perceptions.

Participant: The biggest issue that I've had with treating them, a lot of times, is, once they've been identified and linked to care, trying to convince them to take medication. . . . When they come in, they're very fearful about the idea of medication. Not all of them . . . What they see in their community is, when people are on medication are when they're dying. That's kinda the way that they perceive it a lotta times . . . That's one of the biggest barriers to getting them to accept the idea of taking it. [Provider #02]

An interesting patient experience reported by providers is the positive effect of the medication in contrast to the adverse effects. Some patients would ‘endure’ these side effects and then stop their medication when they became unbearable.

Participant: A lot of times patients feel that, if they’re having a good response, they have to put up with those adverse effects, and long term that’s just not a good mix. People long term if they’re having diarrhea for weeks, months, years, they’re not gonna—they’re just not gonna take—they’re gonna stop taking the medication, so we work really hard at that. [Provider #12]

Their experience of side-effects also re-enforced negative perceptions of the treatment. These perceptions became barriers to accepting treatment and providers emphasized the importance of adequately educating patients on common side effects associated with the regimen they are prescribed before initiating them on treatment. Providers also encouraged patients to communicate their experiences and concerns and have them addressed rather than stopping the medication.

Participant: These are not reasons to stop your medication. These are things that I’m already telling you I know can happen so this is not a surprise. You should not be surprised or worried. You should recognize that no, we can take care of this and yes, please call me and tell me what’s happening so we know, but don’t stop taking your medicine. Talk about it with me or us—the nurse—and let us know what you’re thinking or you’re worried about. We’ll see you back if we think it’s somethin’ else that doesn’t make sense or somethin’ else that we really think is a problem, and it is perhaps a reason to either change your medicine or to stop your medicine at this point.” [Participant #17]

Patient responsibility/ self-management

Another patient characteristic that differentiated persons in the target population was ability to engage in self-management and the willingness to take responsibility for their care. This was evident in how participatory patients were in the care process (for example asking questions). Patients unable to engage in self-care due to low cognitive or functional ability were reported to do well if they had a competent care-giver that

could be depended on to administer their medication as prescribed and ensure that they make it to their follow-up visits.

Participant: In my particular practice, like I said, the ones that are working and really—some of them are very well health conscious, and they know exactly what to do. They're really on top of—like communicating with the e-mail system where patients can send us e-mails. They really wanna know their numbers, are they undetectable, or if they're detectable I can think of these, and I guess they stick in my head more because I respect that they're doing all this—living with this disease and really taking care of it. Then there are others who are just a little bit on the passive side. Whatever we tell them, they will follow through, not a whole lot of questions . . . from what I've seen, the ones that are working and have a little bit higher degree of education, they'll ask questions. [Provider #19]

Patients who were older reportedly had better coping skills and were more likely to make lifestyle changes (such as quitting substance abuse, prostitution, etc.) to enable them become more adherent to their medication.

Participant: In terms of them taking it (*ref: medication*), it's almost like the patients who get it, they keep it. There's a group that get it. There's a group who never gets it. Then there's kind of a group in the middle . . . Lots of times they're young . . . like 18, 20, 21. Girls who come in with their mothers and their mothers are the ones who are [*responsible for their care*], you know, and the patients are like --- . . . They just don't—they're young. [Provider #16]

Self-efficacy

Some of the providers interviewed expressed concerns about patients' self-efficacy to make changes that would enable them become more adherent to their medication. Despite continued education, counseling and efforts at motivation, some patients were reported as simply unable to follow through with sticking to their prescribed regimen. This was (not restricted to, but) especially common among persons addicted to illicit substances or engaged in highly risky sexual behavior. However, some persons over time (especially as they got older) were said to find the motivation and consequently self-efficacy to make the recommended lifestyle changes.

Participant: I have one lady that was a huge alcoholic for years, and years, and years. Finally she said, "I'm too old for this." Her girlfriends had stopped using, had stopped drinking, are in the church, and that's the path that she chose. It was a matter of being a little more mature, deciding that she wanted a job, that she wanted to be a good example for her grandkids. It didn't matter that her kids saw her having these issues (substance abuse). She didn't want her grandkids to see her having those issues. I have a lot of older ladies that seem to have kind of figured some things out for themselves and made these changes on their own. The younger ladies still struggle with it, and I think it's a social issue. [Provider #03]

Others that struggled with medication adherence were those who reportedly felt that they were unable to deal with the side effects or the chronic administration of medications. According to some of the providers interviewed, such persons 'chose' not to take the antiretroviral treatment prescribed even when changes to the regimen were offered. There was an example of one such patient who invariably died of HIV-related causes.

Participant: I had one patient, beautiful woman, who—she stopped her medicine and she knew that that meant she was gonna die. She was okay with that because she couldn't take the medicines. She went into hospice care, she went to live with her sister. Her sister took excellent care of her. That's what she wanted to do. She could not take those medicines. She's probably in her 40s, later 40s I think. She was a young woman. She was a young woman. She had children and everything. She just couldn't do it. We told her, we said, "Any time you wanna change your mind, we can try this again and try to turn it around." She couldn't take 'em. They made her feel so bad. Isn't that amazing? I still think about her. [Provider #16]

Simplifying the antiretroviral regimen, especially to the 'one pill a day' regimen was reported by providers to enhance adherence behavior in some patients because the patients were generally able to diligently take the single dose daily versus a multiple dosing regimen.

Participant: They're able now to take these single pills or one or two pills, as opposed when I first started they would be taking a half a dozen different medications at different schedules throughout the day. It's really hard to keep up with, especially with some of my older people who aren't the most literate in the world. It's hard for them to keep up with, "I have to take this

one with food, and this one without food, this one before bed,” and dah, dah, dah. If you’re not really told how to chart it or how to set it up. [Provider #06]

However, providers also pointed out that for the patients who had an understanding of the importance of the medication and were committed to taking them as prescribed, the complexity of the regimen was not a barrier.

Participant: I will tell you, the people way back when when we first started doing this, and you had drugs like Crixivan, and stuff like that, patients who got it, they got it. It didn't matter what type of food restrictions they were on, they would do it . . . There's some people, once they are committed—yes. They will do it. They will do it. In fact, then you try to get them to change over maybe to something that's easier and they don't wanna do it. [Provider #16]

Developing a Conceptual Model

To generate a conceptual model reflective of the perceived relationships among the factors identified, further synthesis of the eight broad categories that were identified in the thematic analysis of data was carried out. Support was broken into two sub-categories – [1.] perceived support (social and peer) as patient-related and [2.] instrumental support from care providers as a provider-related and therefore inclusive under the provider component. Access to care was placed under the healthcare system component. The result of this inductive process was the regrouping of the categories, sub-categories and the themes under them into four (4) basic components that were perceived as interacting to influence the medication adherence behavior to produce the consequent health outcome in the target population. These are as follows –

1. The socio-economic context
2. The patient
 - Patient illness experience
 - Patient characteristics
 - Mental and emotional health
 - Perceived social and peer support

3. The healthcare system
 - Access to care [availability and affordability]
 - Healthcare process
 - Healthcare structure
4. The care-provider
 - Provider-patient interaction
 - Instrumental support

Comparative Analysis of Conceptual Models

The conceptual models developed from patient and provider interviews respectively were compared to specifically identify similarities and differences in perceptions (Figures 4-1 and 4-2). Comparisons were made based on themes identified under each category

Contrasts in Patients' and Providers' Perceptions

Socio-economic context

Socio-economic context (as previously discussed) was repeatedly cited by care providers as an over-arching theme influencing patients' care-seeking and medication adherence behavior as well as their access to and care process. Their socio-economic status was also said to make the target population more vulnerable to healthcare system related problems. Patients did not make direct reference to their socio-economic circumstance in their narratives.

Provider: It's not only living with HIV but also everything else that goes with it as far as taking care of the family. Many times, they're the head of the household, which puts a lot more pressure on them . . . Taking care of the family, taking care of herself. Then they have so many things to juggle that it's difficult to prioritize what they're going to do. Sometimes they make the wrong decisions. [#09]

Housing as a major barrier: A major issue raised was housing. Many of the providers emphasized the importance of stable housing in HIV care, especially in the

target population. They stated that patients who had some stability in housing were better positioned to engage in care and take their medications as they should.

Provider: I think we talked earlier about what the outcomes are for HOPWA. Every program here has outcomes, but ours are state outcomes. I believe that it's a 90 percent threshold of our clients remain stable in their homes during the service period. Because of that, they have better access to health care, more likely to take their meds, if they have a roof over their head. [Provider #07]

A problem related to housing was previous incarceration and/or having a criminal record. This made it more difficult for some of these women as landlords were skeptical of having them as tenants and the same background disqualified them from getting into public housing facilities.

Provider: Then they need to find housing, and then landlords don't rent if they have a very bad criminal history. Then they don't qualify for the public housing, so it's a whole big problem for them to be stable. [Provider #05]

Patients' interviews did not explicitly identify socio-economic factors as barriers to care and medication adherence. However, data from their demographic profiles such as unemployment and low level of education (Table 1-1) as well as inferences drawn from their narratives did reflect the impact of SES on their health-related behavior.

Patients' HIV illness experience

Dynamics of the transition from states of denial to acceptance: A critical look at the narratives from the care provider interviews revealed that they had a lot of insight into the patients' experience of living with HIV. The various phases were similarly identified by participants in both study samples. However, the perceptions of how the patients in this population go through this experience and what they experience in these phases differed in some ways.

Provider: Then you have a group of patients who don't take 'em because after they start taking them they feel better. That's when maybe a little denial kicks in, if you know what I mean. [#16]

Patient: But it took a lot of years for me to get there. And it took a lot of denial because from the beginning this virus was not real, it was not me, I did not have it. I don't know what you're talking about. And I got tested I would say about six times before I really accepted that I truly had it."[#01]

From care provider perceptions, the initial denial at time of diagnosis was common among patients. However, some patients who had come to accept their HIV status were said to still slip into denial when they achieved viral load levels that were undetectable by lab measures; suggesting that movement between denial and acceptance may be dynamic rather than static for some patients. By implication, patient reversal to denial would also signal a reversal to non-adherence to their medication. However, among participants from the target group, going from denial to accepting their HIV status was described more like a linear process whereby the change occurs at some point in their illness experience. There was no mention of going back into denial after becoming adherent to their medication. However, due to the small and convenient study sample, it is possible that no member of this sub-set of patients who move in and out of denial was interviewed.

Necessity of perceived control of HIV disease: According to providers, perceived control of disease did not necessarily follow acceptance of HIV status for a sub-set of the target population who were identified as living a lifestyle of risky sexual behavior. While “somewhat” accepting their status based on anticipated outcome of their lifestyle, they were not perceived as necessarily coming to a point of ‘perceived control’. However, from patients’ perspective, perceived control of disease could follow acceptance (mediated by HIV knowledge) or conversely could be the result of

empowerment from self-disclosure of HIV status; hence the bi-directional arrow between these two phases in the patient model.

Provider: It's part of the life they've lived. They almost expect it, there are—because of their way—their relationships, different partners, or they were prostitutes or they're drug prostitutes. It's almost like, "Whatever." I've had very few come through that are really shocked and surprised, but a lot of 'em just—it's like another day . . . I don't know that they accept it. I think it's just there. Almost like they expected that it might happen, but they didn't do anything to prevent it from happening. I don't know that they truly accept it . . . **[More or less, would you say they are really not in control of it?]** Definitely. [#10]

Patient: I studied more about the virus, I learnt about it. Not only that I had it, but about it to know it and understand the things that I needed to do so that I can keep it under control. How I could take control of it. I didn't have to allow it to dictate my life. And when I learnt how to do that, I was ok with me . . . I began to take the initiative to take my own care seriously and to take control of it, so I could live. [#01]

Motivation for adherence versus finding purpose/relevance: Having reason(s) to take their medication was perceived by care providers as finding motivation to live. Some of these were also motivating factors mentioned by patients. Providers however cited these factors as 'levers' that could be used to nudge patients into committing to taking their medication and included,

- HIV knowledge (from patient education/counseling);
- prospects of staying on a simple regimen;
- hope of seeing their children grow up;
- care-giving responsibility to family members (children, elderly);
- perceived efficacy of treatment;
- deteriorating health/near death experience;
- care-giver experience of sick relatives;
- faith in God/ spiritual encounter.

Provider: You've got to find—and every patient's different. For some people, it might be children. For somebody else, it might be a parent that's sick and needs their help. You need to be there for your mom. I know she's not doing well. She's got Alzheimer's. She's gonna need you there. You've gotta figure out what it is. It might be love for somebody. They're in a new relationship. You've gotta try to figure out what motivates that person, and

how can I use that motivation in a positive fashion, to get them to be adherent. You have to have a reason . . . You've got to find—and every patient's different. For some people, it might be children. For somebody else, it might be a parent that's sick and needs their help. You need to be there for your mom. I know she's not doing well. She's got Alzheimer's. She's gonna need you there. You've gotta figure out what it is. It might be love for somebody. They're in a new relationship. You've gotta try to figure out what motivates that person, and how can I use that motivation in a positive fashion, to get them to be adherent. You have to have a reason. [#02]

Patients interviewed perceived these reasons in a slightly different context – more in the light of finding the purpose for living or discovering their relevance to significant persons in their lives (family members) and/or the purpose for their lives. Patients described this point in their illness experience as a turning point when they realized that they had a reason(s) to live. These differed from things that in addition, motivated them and included,

- care-giver responsibility (children);
- perceived relevance in children's lives;
- engagement in HIV advocacy activities;
- faith in God/Spiritual encounter;
- perceived love and acceptance by family members.

In addition to those mentioned by providers, patients interviewed also considered the caring attitude of a healthcare provider as a major motivating factor. Worthy of note is that none of the motivating factors cited by providers required the patient to disclose their HIV status; hence being motivated to be adherent was not necessarily a phase following self-disclosure of HIV status. In contrast, most of the factors that gave patient a sense of purpose/ relevance required self-disclosure of HIV status and were associated with relationship with others. Hence this phase of discovery of purpose usually followed self-disclosure of HIV status. While the provider perspective suggests

that patients could be motivated to take their medications as prescribed even when they had not disclosed their status to other people.

Patient characteristics

Substance abuse as an addiction versus substance abuse as a coping

mechanism: Substance abuse was generally perceived by care providers as a predisposing factor to mental health issues prior to HIV diagnosis and a continuing addiction. For patients interviewed, while substance abuse was acknowledged as an addictive lifestyle prior to HIV diagnosis, it was also described as a coping mechanism initiated after diagnosis with some patients especially when in denial of their HIV status.

Provider: Sometimes people, especially those who are addicted to drugs, aren't gonna change, or can't change. Drug addiction is a fatal illness. It should be the same as lung cancer. That's the way we should look at it, in my mind. Addiction is very much a fatal illness a lotta times. It's hard to rescue people from that, but sometimes you can. [#02]

Patient: And I could remember even when I tried a little drug at the rehab and for the first time, I felt peace. So I thought 'wow' and then I didn't have to think about it. It took it out of my mind. For that moment I was happy. I was OK, and then when the high went away, the thoughts came back in my mind and then it seemed like the more I stayed sober, the heavier that weight was on me so I stayed high more. So I didn't have to feel it, I didn't have to face you know the idea that I was HIV positive. And then I was doing this yo-yo thing with my meds." [#01]

'Modeling' as key to change in disease/ treatment perception: For providers, change in disease and treatment perception was attributed largely to patient education and counseling, with consequent increase in knowledge and understanding, and perceived efficacy with continued adherence. In addition to patient education/counseling and perceived efficacy, a significant key to change in disease and treatment perception identified by patients was "modeling" by other PLWHIV. This involved observing and learning from someone else who was living effectively with the virus. On the other hand,

providers were not very familiar with the role that other PLWHIV could play in changing patients' disease and illness perceptions in the target population.

Provider: I just found out in another conference that there are peers who have HIV—volunteers who are willing to talk to . . . and I think we have to make more use of them. [#19]

Patient: And he start talking to me. He said you got the stuff and I say yes, and I figure well he and I got it. I got HIV and he said since 1989. OK. He gave me a big lift up. He did, he just talking and talking He just gave me a big lift up. And I say . . . he's 65 and looking good. [t#9]

The etiology of mental health problems: Mental health problems – cited by providers as a major issue in antiretroviral medication adherence; was perceived by providers as often pre-existing the HIV diagnosis and attributable to substance abuse, domestic violence/ sexual abuse and HIV-associated depression. While HIV-associated depression was commonly experienced at diagnosis and especially when in denial, none of the patients who participated in the study mentioned having a history of mental illness associated with substance abuse or sexual abuse – possibly because of perceived stigma.

Provider: There are mental health issues. I think with any population—with this population, there's definitely a lot of mental health issues. The things that go with long-term drug abuse as far as the brain and how it responds; not taking care of themselves and getting critically ill so they end up in the intensive care unit. [#13]

Patient: Like I said, I have my good days and I have my bad days. I go through my depression, I go through my anxiety attacks and panic attacks, and you know I go through it. But if me and her get on the phone and we talk or we go out for lunch, or whatever, I overcome that. Cos she's much older than me and she understands where I am still. [#7]

Cognitive ability related to self-management: Patients' cognitive ability was perceived by providers to be correlated with their ability to engage in self-management and participate actively in their care. Impairment in cognitive ability was cited as a major

barrier and such persons affected were reportedly dependent on care-givers for their healthcare. This did not come up in patient interviews. However, this may be because those who volunteered to participate in the study did not have any significant cognitive or functional impairment, since they were mentally functional enough to engage in an in-depth interview.

Provider: Other patients, never get it. There's some patients you just have to realize at a certain point it's a cognitive issue. It's a cognitive issue. No matter what you do, they don't get it, yeah. I know. You can try, but that's where it's really important to have a family member involved if you can because they're never gonna get it. Like that one little girl I told you whose mother died, she was never gonna get it but her mother got it. Her mother made sure she got the pills and made sure she got the appointments and did the blood work and did everything. She wasn't gonna be able to do it herself. [#16]

Faith in God as a facilitator of self-efficacy: A factor that patients identified as increasing their self-efficacy to make lifestyle changes and consequently enhance medication adherence was their relationship with and faith in God. Even though there was some mention of the religious nature of this population, providers did not readily make the link between their faith and self-efficacy as related to behavior change and consequently medication adherence. However, two of the providers did mention that patients who were religious did do better with the treatment.

Provider: I'll ask 'em, "Do you have a spiritual life?" That's something, and particularly in this community, I want to know. I definitely wanna know that. If they don't, that's okay, but I do tell the people that have one, I'm like, "This is great news to me. I can tell you, my experience, people who have a spiritual life, they can put some of their burdens on somebody else. With prayer, they tend to do better. I encourage you to develop that." [#02]

Patient: You know I have a friend that always says "That drug is out there hitch-hiking, just waiting for you to pick it up." Also, I never put myself in those places where I have to pick up ----- so I'm pretty good now. Though there's always that thought in your mind "will I ever do it again?" And the way I have seen what I left out there, you know and just to pass by and look at

it, it's like "My God, was I like this?" And it's not getting any better, it's getting worse. So my right thing is just to stay focused and keep the Lord on my side. You know that 's the only thing I can do because He's the one that brought me out of this. I couldn't do it myself. [#03]

Complexity of regimen versus chronic administration as a significant

barrier: Providers identified the change of prescription to a simpler regimen as increasing self-efficacy to stay adherent to their medication. The complexity of regimen though raised by some as a challenge did not necessarily limit medication adherence. Patients interviewed placed priority on the factors that motivated them to take their medications and many said that once they committed to taking their medications, the complexity of the regimen (considering also co-morbidities) and/or side-effects became non-issues. What patients complained about was the overwhelming thought of having to take these medications continuously with no break for the rest of their lives

Provider: A lot of our new patients we have to put on the one pill once a day. When you have a patient on one pill once a day they're way more compliant, especially the new diagnosis patients; not just the women but anybody. One pill, once a day is definitely always better. [#18]

Patient: I had periods when I stopped taking them. **[Why?]** It was just too much to handle, and I got tired, and sometimes when I took them I got sick. I mean every day? Come on! [#9]

Providers did acknowledge that the regimen was not as important a factor for a sub-population of patients in the target population who were already determined to take their medications. In fact, some were averse to switching to a simpler regimen especially if they found the more complex regimen to be effective in controlling their condition.

Provider: There's some people, once they are committed—yes. They will do it. They will do it. In fact, then you try to get them to change over maybe to something that's easier and they don't wanna do it . . . I've had patients like that. I have this one darling patient from Georgia. She's on a weird

regimen right now. A regimen we would never start now, but she's doing just fine. [#16]

Perceived significance versus actual experience of peer support in HIV

care: Peer support was perceived as potentially beneficial; but no firsthand account of impact on health-related behavior was given by any of the providers interviewed.

Among the patients interviewed, peer support was cited as significant in facilitating adherence in the target population; personal experiences were narrated to support these claims.

Provider: Going to these support groups I think is helpful. To talk with somebody who just went through this not too long ago, and is understanding. Sometimes it's hard to talk to somebody that doesn't know. You can tell me all about the side effects to your medication, and I can say, "Oh that sounds awful." I have no idea. [#08]

Patient: Like I said, I have my good days and I have my bad days. I go through my depression, I go through my anxiety attacks and panic attacks, and you know I go through it. But if me and her (PLWHIV) get on the phone and we talk or we go out for lunch, or whatever, I overcome that. Cos she's much older than me and she understands where I am still . . . [patient#7]

The healthcare system

Access to health care services: With the exception of one factor (lack of knowledge), access to care issues identified by providers were not mentioned by the patients interviewed. For linkage to care, providers emphasized the unavailability of some types of services (such as mental health) and whether the patient had coverage or assistance to pay for the services where available. The major access issue resonating throughout the narratives however was transportation. From patients' perspective, the key issue with access to care was patients' not knowing what services were available and where to access them due to inadequate patient education following diagnosis. Transportation was not cited as a problem by patients. However, it is

important to note that the participants interviewed in the preliminary study likely did not have transportation problems since they were all able to come out and participate in the study.

Provider: They have to have transportation to get there, and transportation is probably the biggest problem. There's no public transportation. If they have Medicaid and they are functional enough to make their appointments three days in advance . . . [#03]

Barriers associated with the healthcare process: Barriers cited by care providers as associated with the healthcare process included policies that were perceived to be more restrictive than inclusive as discussed previously. In addition, there was strong emphasis on the excessive paperwork involved in staying in care on a continuous basis. Health care process concern expressed by patient participants was the nature of the referral at the time of HIV diagnosis. Active referral (making appointment for patient and facilitating clinic and follow-up visits) was perceived as more effective in getting the newly diagnosed into care versus passive referral (where patients are told to make appointment or simply asked to go to the hospital).

Barriers associated with the structure of healthcare: Barriers associated with the structure of healthcare as perceived by providers included – fragmentation of the system, inconsistency of provider in specific settings, and concerns over privacy (in specific clinic settings). Of the barriers listed from providers' narratives, only inconsistency of care provider was brought up by patients as a structural barrier. Some patients however did not consider this a barrier. These patients felt they had no choice and simply accepted that they may be seen by different providers at follow-up visits. They did recommend that the different providers should communicate more effectively to ensure that they are all on the same page regarding the patient's condition.

Patient: I see different doctors . . . They're all . . . they're pretty much the same. I think they might need to talk more to each other about, I mean if you're gonna see someone different at least they should be informed on what's going on. [#05]

Provider-related factors

Provider-patient communication – There were three communication issues identified by providers – [1.] information over-load following diagnosis, [2.] redundancy of information in the process of care, and [3.] language barrier. They talked about the counseling protocol at the time of HIV diagnosis; where effort was directed at giving the patient information on so many different things pertaining to HIV and the treatment. Many of the talking points were as a matter of policy required to be covered following diagnosis. This however, tended to make patient counseling at the said time a checklist.

Provider: When a person is told they're positive it's a process. It's like a paperwork process that they have to go through, especially when it comes to the department of health. They just go by the book. They're like here is—they give you a pamphlet on what's going on. They give you a pamphlet of what medications are there. They're supposed to give you your options of the providers you can go see and that's it. It's just a step-by-step process that they have to follow that the case workers or managers or whoever the people are, they're supposed to follow. Then you tell this person—you give them all this information—that person doesn't know what to do. They're like, "Oh, wow." They just go with what their first option was given to them because they really don't take the time to—they're so shocked with everything and it's just thrown at 'em. [#18 – *information over-load*]

Providers acknowledge that patients at the time of diagnosis were unlikely to retain much of the information given to them and rather needed to have their immediate concerns addressed

Provider: The women who are still overwhelmed with all the information—they often will respond, "Oh, well you've told me everything. I don't need to hear more." I don't honestly take that as I actually did a great job. I take that as this is still overwhelming for them and they can't even sort of get to what are their questions really. People will ask questions or they'll focus on some particular thing that's of interest to them, so I'm also listening.

What are they asking about? Are they askin' about havin' a baby? Are they askin' about taking medicine? Are they askin' about in their family or with their partner? Is there a risk or what else, or are they asking about just coming back to medical stuff? I'm trying to also listen to what they're, quote, worried about or what they're paying attention—what's important to them? [#17]

One of the providers pointed out that some of the care providers (particularly physicians in the academic setting) who were foreigners had hard-to-follow accents that made some of their pronunciations difficult to understand. The point here was that most patients in the target population were unlikely to ask the provider for clarification when they did not understand what they were told.

Provider: The language barrier with some people who come here is—I'm not sure if people want to say, "I don't understand you." They'll just say, "Yes, yes, yes." I just thought of that. Language barrier might play a part in how people follow up on their adherence, their care and what have you. I think many people are very good but there's some—you know some people have a way of being able to—I mean to me, you or—I don't know where you came from, it doesn't matter. I think you're very—you really enunciate well so with your accent I think anybody could understand you. There's other people that if they mumble or whatever there's—people just, "Yeah, yeah, yeah, yeah, yeah," and then they leave— - and it's sort of like, "Well, I don't know what I'm supposed to do." [#13 – *language barrier*]

While continuing education was recommended for patients who had been on ART for a long time, some of the providers pointed out that at a point, some of the information became redundant especially if patients were adherent to their medication.

Provider: I know that it's a big pharmacy counseling point, but I find that it's very, very beneficial to find out where someone is before you bother to go into the long spiel about all of the medications, and what they're doing, and how to use 'em, and how to take 'em, and the little nuances of them, which I think are important but maybe not necessary for every single person. Because I find that that population who comes to me is generally in the middle ages, I wanna make sure that I'm not assuming that they're brand-new to it or that they're incompetent. [#20]

In contrast, other providers were of the opinion that no matter how often a patient had heard the information, it should continue to be re-iterated at follow-up visits.

Provider: Well, I've learned from the physician. 'Cuz I've learned, listening to him tell the patients what to do and how to do it, I've basically learned from him so I just go off by what he says. You know, "Take your medication every day. If you need any resources we can get them for you. Here's this pharmacy, here's that. Here's a pill box. He basically does the same thing. He gives them their little lecture about, "Take your medication every day. Your numbers are good. Blah-blah-blah." That's basically it. [#18]

Concordance in Patients' and Providers' Perceptions

Patient illness experience

Perceptions of the phases in the patients' illness experience were relatively similar for the participants from the target population and the care providers interviewed and both included being in denial, acceptance of HIV status, perceived control of disease, self-disclosure of HIV status and having motivation to take their medications.

Denial: Denial was acknowledged by both patients and providers interviewed as a common experience following HIV diagnosis.

Provider: It would vary a lot across the spectrum, particularly in the people who are recently diagnosed. They just have no idea what's happening and they're afraid. They don't really wanna talk about it much anyhow, right? They'd rather it just would go away. [#17 - *Denial*]

Patient: I was in denial. I did not want this to stare me in the face. And keep me depressed or anything, so I didn't get care. I was at the point that I didn't care if I lived or I didn't. [#07 - *Denial*]

Acceptance of HIV status: With time, patients came to terms with their diagnosis and became more accepting of their status. While providers credited education and counseling with changing patients' perception and facilitating acceptance, patients in addition talked about the impact of seeing other person(s) who was living with the disease. Both patients and providers generally agreed that before patients became adherent to their clinic appointments and medications, they more likely than not were at the point where they were accepting of their HIV status.

Provider: Most of the time they've accepted, or are at least on the road to accepting, and they just want help . . . Most of them, yes, are very—they've accepted, or at least are still internalizing it . . .[#08]

Patient: And even though I do have this virus, I look at the difference on ---- he or she has AIDS, ok to me that's just a big word, it's a negative word. Yeah it's reality but it's a negative word. No, I have HIV, am HIV positive, I have the virus, there is a difference. [#02]

Perceived control of HIV disease: Following acceptance of their HIV status, increased HIV knowledge, and a change in their perception of the disease and treatment some patients would come to understand that they could keep the infection under control versus perceiving it as a helpless or hopeless situation. At this point, patients were then more likely to commit to improving their medication adherence behavior.

Provider: But they understand now that this disease isn't going to kill them, that they have control over the disease. If they can learn that they can control the disease and not let the disease control them. [#01]

Patient: So I set my mind and I say this is what I gonna do. I'm not drugging and drinking anymore. I'm gonna take my drugs and that's just it. That's what I did. I just put myself in a positive place and feet firm on the ground, and that's where I stayed. Is that is where am staying today. [#02]

Self-disclosure of HIV status: Members of the target population were reported by both patients and providers as really averse to disclosing their HIV status to other people. Generally, over time, many of them (especially if they had accepted their status and gained some sense of control over the condition) would tell family member(s). Most times, family members were accepting and expressed love for the patient in spite of their HIV status. Self-disclosure also led to the availability of social support.

Provider: Eventually, though, they do make that effort and tell them (reference to family members), and then they have good social support . . . Over the years, they've told them, and then finally they have come to terms with it. [#19]

Patient: Well at first I was afraid to tell them because I didn't want to be an outcast. And I thought that's what I was going to be like. I mean they loved me and that's all that mattered. Once I told them, to be honest once I told them, they told me they already knew. Once I told them (family). So they didn't treat me no differently . . . you know like I thought that was going to happen. Em . . . they're just a good support system. [#5]

Motivation/ finding purpose or relevance: To become adherent to their medication, persons in the target population often needed a reason to make that commitment of a lifetime of chronic drug administration. This was viewed as having motivation from the providers' perspective, but patients described it as a point of discovery of purpose or relevance. Either way, at this point, patients had a reason(s) to stay in treatment and take their medication as prescribed. Having this knowledge, providers talked about nudging patients to this point to facilitate medication adherence.

Provider: You've got to find—and every patient's different. For some people, it might be children. For somebody else, it might be a parent that's sick and needs their help. You need to be there for your mom. I know she's not doing well. She's got Alzheimer's. She's gonna need you there. You've gotta figure out what it is. It might be love for somebody. They're in a new relationship. You've gotta try to figure out what motivates that person, and how can I use that motivation in a positive fashion, to get them to be adherent. You have to have a reason. [#02]

Patient: Even though I knew this medicine was doing this to me (side effects), it didn't matter because I had a purpose to live – my daughter. And it's just like this – and you just become where you put in your mind psychologically, this is what I need to do, then this is what I'm going to do. Cos I had too many people to disappoint – and me being mainly, my family being another, God being another so then I --- you put your mind to something and there ain't nothing that you can't do. [#02]

Patient characteristics

With the exception of mental health problems, the same major barriers and facilitators were identified by both groups as possibly having a mediating effect between patients' illness experience and their health-related behavior. The contrasting sub-

themes are discussed in the previous section. Similarities in the themes identified are presented as follows -

Patients' disease and treatment perception: The reportedly low knowledge of HIV at the time of diagnosis and the prevalent normative beliefs influenced the perception of patients in this population. This perception was thought to contribute to making them hesitant in accepting antiretroviral treatment. Providers usually took on the task of educating patients to change their perceptions about the disease and also the medications.

Provider: The other thing that I see happen—and I've had a couple of female African American patients tell me this—is they're fearful of treatment, because so many people access treatment when it's too late or almost too late; they're very sick. Then they associate them going for treatment and the medication as dying, or that the medicine is killing them somehow. [#02]

Patient: Because of the stories. There are a lot of bad stories about HIV meds. I was on AZT and I stayed on AZT off and on for quite some time. And people were dying is what you're hearing anyway, from this medication because it was so strong. [#1]

Medication-related experience – side-effects: The experience of adverse side effects was a significant barrier identified by both providers and patients. This was more so a problem for patients initiated on treatment when they had not had any HIV-related illness, hence the side effects made them sick. Providers emphasized the role of patient education and drug information prior to initiating treatment so that patients are aware of potential effects and possible courses of action in their event (prescription of other medications to combat side effects, switching to a different regimen). There were patients who did stop their medication because of the side effects experienced.

Provider That's the first thing because if you do not tell them about side effects upfront, they may start takin' these meds and they started gettin' diarrhea

and throwin' up, they'll say, "I'm not gonna take this. I was feelin' fine beforehand, now, no!" [#11]

Patient: When I first started they used to make me very ill. I was like, I mean nauseous all the time and I was thinking that maybe they were giving me the wrong meds or it was too strong or whatever. And I would come back and ----and there was one particular one that I really thought was doing the damage and I just completely stopped taking it. [#03]

Patient responsibility/ self-management: Another patient characteristic that was identified by both patients and providers was the ability of the patient to take on the responsibility for their health, engage in self-care and be involved in the care process. When patients assumed this responsibility and became proactive with their care, they reportedly had better care and health outcomes; including adherence to their medications.

Provider: People really need to take responsibility for their care . . . it's like, "These are the tools. When you're ready for it let us know and we'll just keep on trying to get you going but you've got to be the one that's willing to do it." [#13]

Patient: I'm very pro-active with my medication, because I want to know if this medicine is going to interact with the other medicine. What should I do if it interacts with the other? . . . I'm the person that wants to know "what's the side effects?" I wanna know if they gonna make me gain weight, lose weight, is my eyesight gonna go or what? You just don't wanna give me something that I don't know nothing about [#7 – *adherent to her regimen*]

According to providers interviewed, active participation was also associated with maturity; older women being more likely to take on an active patient role compared to younger women. Younger women were described by providers as being likely to be dependent on a care-giver than taking responsibility for their care.

Provider: Oh yeah, like 18, 20, 21. Girls who come in with their mothers and their mothers are the ones who are, you know, and the patients are like, "Me?." They just don't (*get it*)—they're young. [#17]

Generally, this population was described as tending to be more passive in their patient role. Many of them were not likely to ask questions and one of the providers suggested that this may be due to their level of education and simply not knowing what questions to ask.

Provider: People are not educated and a few of the African-American women I have seen don't know how to ask the questions. [#18]

Provider: I think it's good that you asked that question. That's probably the only thing I would say that—that I would say like sets them apart. They don't ask too many questions. Not passive. I think it's something that's holding them back, no matter how much you try. I think asking questions, yeah, that's probably the only thing I would say that probably—and that might be different with them . . . I would say asking questions, probably that's something that they can—that surely would help them, you know, and help us, because any help to them is help to us, so yeah, I would say like asking questions would be a good thing. [#14]

Perceived social support: The importance of having a social support system was emphasized by both providers and patients. It was recognized as a critical factor in coping with HIV. Having social support served to increase patients' ability to maintain their health. Family members would often accompany patients to their follow-up clinic visits and encourage them to take their medications.

Provider: I think the social support is very important for patients to be able to maintain adherence. It was variable. Some of the patients I remember in clinic had spousal support. That was very good too . . . Or a parent. [#16]

Patient: Whatever way it is find your support. Whether it is with family, or with a friend, or --- you need that support in your life cos if you don't have it, you will go down living with this disease, but if you have support, you won't go down. [#7]

Perceived peer support: Peer support as previously discussed was support derived from persons who were also living with the HIV virus. There was a mutual recognition that this was a type of support different from the emotional support of loved

ones. It was based on the understanding that this 'person' understood them and could genuinely identify with their circumstance and challenges.

Provider: Going to these support groups I think is helpful. To talk with somebody who just went through this not too long ago, and is understanding. Sometimes it's hard to talk to somebody that doesn't know. You can tell me all about the side effects to your medication, and I can say, "Oh that sounds awful." I have no idea. [#08]

Patient: Like I said, I have my good days and I have my bad days. I go through my depression, I go through my anxiety attacks and panic attacks, and you know I go through it. But if me and her (PLWHIV) get on the phone and we talk or we go out for lunch, or whatever, I overcome that. Cos she's much older than me and she understands where I am still . . . [#7]

Self-efficacy to make lifestyle changes: Often, patients engaged in behaviors that constituted barriers to medication adherence had to perceive themselves as being able to change these behaviors in order to maintain their health. With maturity, patients were said to become more committed to the recommended behavior. The patients interviewed were mostly middle-aged and they talked about becoming consistent with abstinence from illicit drugs, alcohol and prostitution over time as they got older and wiser so to say.

Provider: I have a lot of older ladies that seem to have kind of figured some things out for themselves and made these changes on their own. The younger ladies still struggle with it, and I think it's a social issue . . . I think as they get older they go, "Who cares anymore?" and "I'm tired of this chaos. I'm tired of these relationships that are a disaster." They (older women) decide to be abstinent or have one partner, and they get stronger in themselves. I think a lotta my ladies are very strong now, and they're able to say, "Hey, you know what? I'm not a kid anymore. I don't hafta play your games," so they set the limits on the guys as they get older. When they're younger they have a hard time doing that and I guess it's a cultural thing. The guys are more with the heavy hands, and the women kind of feel like they have to be subservient a little bit to that. That's been pretty interesting, I think . . . Most of my ladies over 40 are very adherent. Almost all of 'em have an undetectable viral load. They just work hard. They really focus on their health [#03]

Patient: Then even though my health was getting better, it wasn't getting as better as it should have because I was still . . . I wasn't drugging but I was drinking. So then I learnt that there are certain things I couldn't do to stay healthy. And if I did take a drink, I could drink maybe in moderation and not like . . . I learnt that and I learnt that . . . because I relapsed once because of people, places and things. I learnt that I couldn't go just anywhere, I couldn't hang with any kind of people, I couldn't go to certain places. I had to cut off certain friends in order to stay clean. I had to change. I changed everything that I could because I chose that life was better than being dead. And in my mental state when I put the virus in its place my mental state changed because I stopped feeling sorry for myself. [#01 – over 40years old]

The Healthcare system

Access to care - lack of knowledge of available services: Care providers identified several issues associated with access to care in this population including insurance coverage, assistance, and availability of HIV care-related services and particularly transportation. The point on which there was concordance between the two groups of study participants is the patients' lack of knowledge of the available services. Providers acknowledged that access issues encountered by members of the target population were not necessarily about the availability of the needed services. Even where the services were available, these women did not necessarily know about them. Some of the patients interviewed said they were not told where to go to for the care services they needed.

Provider: Sometimes, I think the biggest tragedy that African-American women have when you're dealing with access to healthcare is there are services out there and they don't know about it and they don't know how to access it. If they could access it, then that'd be great help. [#11]

Patient: But as far as telling me about where to go, or seek help or counseling – nobody never told me that. I kinda did that on my own. [#02]

Healthcare process- active versus passive referral: The process related component that both patients and care providers perceived as a barrier to care for the

target population was the referral process. The case manager described the current care protocol as involving immediate efforts to link patients to HIV care-related services. However, how receptive patients were to these efforts was influenced by their mental and emotional state at the time of diagnosis. Engagement in care was still very much up to the patient. Patients described the active referral process as literally having someone else undertake the responsibility of the linkage process. Newly diagnosed patients were more easily linked to HIV-related care services when the referral was facilitated by a fixed appointment and instrumental help such as transportation to the clinic. In passive referral, patients were simply given the information and expected to follow-up with making and keeping the follow-up clinic appointment and accessing other services like financial aid and mental health.

Provider: The Health Department contacts them. Then they will give them our information and help them. Then they contact us. Then we do the initial intake to get them help with the services that they might need . . . They try to link them at the Health Department, but you can't make somebody make that phone call. [#08]

Patient: When I got the news they immediately made the appointment for me because see at that time I was living out in (*name of*) County at that and they made doctor's appointment for me so I could immediately be put on the meds. [#08]

Healthcare structure – consistency of healthcare provider: Care providers talked about various problems with the way care is structured; factors which they perceived as constituting barriers to the target population. These included privacy of the care-setting, waiting times and fragmentation of the system. However, the structure-related issue that seemed to be of some concern to the target population (which care providers in the private clinics also picked up on) was the consistency of the care provider.

Provider: The other thing that is important when you're trying to reach out to people, I think, is they need to get to know you and know that you're there for them. One of the problems that some HIV clinics have is they're rotating providers in and out all the time. I think that that's really difficult to do with this population. It's much easier to do it for a more educated population than one that is really in difficult circumstance. [#02]

Providers in the academic healthcare setting agreed that while this could be a problem, there were also efforts to ensure that patient preferences with regards to who they saw was respected. In addition, they also said that they tried to build a relationship with the patient as a team and were careful to share information relevant to the patient's care with the aid of electronic patient records system.

Provider: We do give you the choice of seeing someone or not seeing someone because you might like me and like two other people, but you might not like the fourth person or whoever it is . . . There are some patients who specifically ask not to see one of us, and we completely honor that . . . we try to give that choice and try to give that coverage. At least they're seeing the same fellow or the same attending. [#15]

Provider: The way that we go about it is—the good thing with the electronic system is it tell us who saw this patient before. If everything's great and this patient is being controlled for two or three years, we'd like to just go ahead and see them and ask them is it okay. If it's in the early stages, we try to have the same person see them. If they're having an issue, we try to always make sure that person sees the same provider. [#15]

One of the patients' interviewed narrated a bad experience she had that she considered attributable to the inconsistency in care provider. From her story, it was evident other factors like that individual provider prescription preferences and a lack of communication between providers could result from the rotations.

Patient: Keep changing doctors. That's not me. And then they got to send you out for testing. Then they got to get your test results and all that. Me, where I get my care at, I see that one doctor . . . This week I may see one doctor here, next week I may see another one. In the health department they need to have one specific doctor instead of having . . . that's my bad experience with them. (So how did that affect you?) Because they went to

changing my meds . . . one doctor's got you on one medicine that is doing you good, then one doctor change you to another medicine that he thinks is better for you. I don't understand that. You didn't give me the chance to see if this medicine is going to work . . . I think they might need to talk more to each other about . . . I mean if you're gonna see someone different at least they should be informed on what's going on. [#5]

Care-provider related factors

Provider-patient relationship - There were four characteristics of the provider-patient relationship that resonated in the narratives from both groups of participants as being important to the target population. They included - [1.] accessibility, [2.] perception of care/commitment from the provider, [3.] personal knowledge of patient and [4.] building trust in the relationship.

Both groups emphasized the importance of the care provider's availability and accessibility to the patient outside the clinic appointment and even after work hours. Patients' ability to gain immediate access to their provider often resulted in solving problems that could have led to a discontinuation of their medication. Providers could schedule for the patient to come in earlier than the booked clinic appointment and address their concerns (for example side effects). Patients evidently gained a sense of confidence in knowing that their provider was 'within reach'.

Provider: When they come in, we sit down and we talk. I reassure them that I'm here. Here's my private phone number. If you have any questions, you know you can call me. . . . Every HIV patient I have has my private cell. Each one has my own private cell if it's an emergency cuz I can open up this pharmacy if we need to and get medicine for them. It's just really important that they learn . . . that they know that you're accessible. [#11]

Patient: I even call my doctor – I get my doctor at 3-4am in the morning . . . I have her direct number . . . She said, you can call me any time. If you get sick 2-3 o'clock in the morning, call me. I'm there with flying colors . . . I'm there, 'cos we have that understanding. [#07]

A mutual point that was greatly emphasized was the demonstration of care and commitment by the provider. This notion that the care providers viewed themselves as stakeholders in the patients' wellbeing was perceived as important by providers and acknowledged by patients as critical to their response to care.

Provider: They have to know that you care about them. If you can do nothing else that first visit, if they leave there thinking, "You know, I kinda like that guy," or gal, you have made a start. If you don't—if they do not understand that you care for them and you really want the best for them, they're not gonna do what you ask 'em to do. If you can get that across to them over the first few visits, that is what I think you need. That's the foundation that I try to work on. The old trite phrase that's used sometimes is, "They don't care how much you know until they know how much you care." It's really true, especially with this population. [#02]

Patient: The thing is, she was more than a doctor. She was a friend, she cared. It was like . . . she had a caring attitude. She cared about how it would affect me; about me period. And that made a difference. She cared. She said I was her patient. I'm in her care. And she was responsible for me. [#06]

Consequent to showing care and commitment, patients agreed that they thrived more when their care was handled by a provider that knew them personally. In fact some patients would refuse to see a provider that they felt did not know them on a personal level.

Patient: My doctor's gonna have someone else over and she's on vacation? I ain't gonna see that other doctor until my doctor come back. It's because I feel that that other doctor don't know me. Even though thy done read my chart and everything, they just don't know me. They assume, but my doctor knows. You see what I'm saying . . . Like my doctor knows if I come in . . . nose congested and coughing, they already know they need to nip that in the bud right there, because I could go into other complications. So they don't . . . my doctor knows this but the other doctors don't know that so they go like pushing it under the rug – she just got some congestion going on, she'll be alright. Let's give her ----- and send her on her way. Then I'm back to square one. Laying up in the hospital through the whole 9 yards, but if I was seeing my doctor, I could have prevented it. That's just me.[#07]

Providers acknowledged that it was important to know the patient in order to effectively care for them. Knowing the patient however entailed spending reasonable time with them and understanding not only their medical problems, but the context of their lives. They also perceived that knowing the patient gave the patient a sense of confidence in the care provider's competence to meet their care needs.

Provider: You have to know them . . . You get to know your patients. You figure out what their problems are. Get to know your patients. Understand what's going on with them. Walk in their shoes as much as you can. . . . Getting to know your patients. They have to believe in you. They have to feel that you care about them. You can't fake it. You cannot. It's hard to fake anything in medicine, but you definitely can't fake it with this population. They have to believe that you really want to help them. If they believe that, then great things can happen for them, because then that gives them the ability to start making changes in their life. Once they start making changes in their life, it's like a fire; it starts catching on. You start seeing great things happen. [#02]

Because of the historical distrust of the healthcare system by this population, providers said in their interviews that it was necessary to build trust with persons from the target group. Building trust was also said to boost patients' confidence in the ability of the provider to provide effective treatment. Patients in their narratives talked about the process of gaining trust in their providers and how it inspired them to take their medications.

Provider: They're usually not real forthcoming initially. It takes quite a while before they'll start to open up. It's usually some time because they don't trust you. They don't trust you. It takes quite a while to establish that. [#06]

Patient: Well first I didn't want to be on medications cos I didn't think that I needed it even though I was tired and everything. I just felt that they were trying to use me as a guinea pig . . . just to test out new medicines on me. But then I thought about it a minute and I umm realized that they're just trying to help me. So if they say I needed the medicine then I must really do need the medicine. [#5]

Provider care approach - There were many components of the care approach that participants from the care provider study sample touched on in their narratives. The care components that aligned with patient perceptions of what was important to them (patient-centered) were the following – [1.] being non-judgmental, [2.] treating patient as a person, [3.] giving holistic care, [4.] physical touch (that to them signified a human connection), and [5.] positive re-enforcement

There was great emphasis by both providers and patients on providers having a non-judgmental attitude towards patients. Persons in this population were described as being very vulnerable as a result of their historical, social and economic context and were therefore sensitive to any attitude that they perceives as judging them. Providers said they took extra care to establish a non-judgmental atmosphere in the care setting. One of the patients interviewed drawing from personal experience had some words of caution for care providers.

Provider: They know that our clinics are a no-judgment clinic . . . I try not to make it a situation where there's any judgment When we talk about risk factors, I try to have no judgment I say things like, "I am not in your shoes. I don't know what decisions I would make had I been in your shoes. Don't ever feel like I'm judging you about anything. [#03]

Patient: (*To providers*) Be more caring, more understanding, more generous, more . . . don't think that it's African American women alone that is living with this. Don't stereotype us. Treat us like we are individual persons. Don't treat us like we're piece of trash. No we're not. Treat us the way that you wanna be treated. [#7]

The practice of addressing patients' problems and offering solutions was acknowledged by both groups as helping to facilitate medication adherence. Providers talked about the emphasis they laid on this with their patients; assuring them that any problems they encountered could be 'fixed' hence they were advised to make their

concerns known. Patients who had their medication-related problems solved were more likely to continue to take their medications.

Provider: If they have barriers or reasons not to be on the medication, I try to overcome those through gentle suggestions . . . If you have a little side effect, I can probably fix it, maybe with the use of a little medicine. For instance, if you get diarrhea, I can give you a pill to stop that, and you can still take the medication successfully. [#02]

Patient: ***[Are there any particular things that the doctors did that helped you?]*** Yeah, I would say that they ummmm . . . They were there for me, you know like when I would come in and discuss things with them and the problems I was having. They make it right. Like my meds and stuff. Sometimes, I might have some reactions from my meds, and they make it right . . . [#08]

Effective care in this population was described by providers as one that was holistic; encompassing all aspects of the patient's life. This perspective acknowledges the impact of HIV disease on the patient beyond their health status. In the patients' narratives, it was also clear that the issues that they struggled with was beyond physical health and included the emotional, social, economic and even spiritual aspects of their lives. When other issues in their lives were addressed, patients were then more likely to focus on their health including medication adherence.

Provider: I think if you're really up front, if you're—you should be, because HIV practice right now, it's just more than medicine, quite honestly, because that is a stigma attached to it, like you don't want to come across as a medical healthcare provider. You want to actually be coming across like a sort of a holistic one where you're ready to help them through whatever issues they're dealing with at home, and then, you know, and yes, inserting the HIV care into it. [#14]

Patient: There was a time when I had no gas money to get here. And the car wasn't running good to get here --- but I had a good case manager that was here. She was the sweetest lady. She made arrangement for the bus to come and get me from my house---- it'll pick me up cos I didn't have the money. When I had this (*mentions a condition*), she heard it one time, she came to my house, talked to me about it. And when I was in the hospital she came to see me and brought me a pretty little stuffed animal. [#06]

The phrase “treat as a person” was recurrent through the narratives of both providers and patients. Providers identified this as an important approach in caring for this population and patients likewise acknowledged the importance of being treated as a person.

Provider: Treat them like a person, basically. That’s all you got to do, treat them like a person because they are a person. We all want to be treated the same. [#20]

Patient: I applaud the healthcare system . . . they’re some great people. And they treat you like a person and not a number. And em that’s important to me to be treated as a person, because I’m a person and that’s important to me. And every time I go to the health dept. I get treated like a person instead of just a number.

Physical touch was cited by a few of the providers as critical to care in this patient population. It was seen as a demonstration of care to the patient as well as a reassurance that their condition did not make them any less human or unworthy of care. One of the patients interviewed in the preliminary study narrated an experience that depicts the importance of human touch to a person diagnosed with HIV especially from a care provider.

Provider: When you come in contact with a person—especially somebody who’s newly diagnosed with HIV—I’ve noticed if you touch them, even if you just pat them on their shoulder, it makes a big difference because they realize you’re not afraid to touch them. When you walk into a room and you shake their hand you just see their face light up ‘cuz they see that you’re not afraid to touch them . . . I feel like that’s how I build relationship; I’m not afraid to touch them. Even with my primary care patients, when I call them through the door I’m like, “Hi, my name is -----. I’m gonna be hanging out with you for a little bit.” That kind of stuff. It does make a big difference when you have that communication of not being afraid to shake somebody’s hand or smile at them. It makes a big difference and it helps the patient open up more to give you that history you need from them. [#18]

Patient: So you're sitting across from a person that is telling you this with their hands kinda folded up anyway, they're pulling back. Even when they are telling you, they're pulling back. So they are rejecting you as they are tell you that. To get up and come around that desk and reach out to them would be . . . it would be phenomenal . . . Because I never will forget, I never will forget when they told me. And it was like, there was three people there, not one of them touched me, except to shake my hand on their way out of the door. (long heavy pause). That's not what you do to someone who you have just told that they are HIV positive (voice breaks on a sob). So that stayed in my mind until that day that (mentions doctor's name) made me feel like I was somebody again. [#01]

According to the care providers, any little achievement was worthy of celebration and could re-enforce the positive health-related behavior that led to it. One of the providers described how they would even celebrate a patient showing up for a scheduled visit. On the patient's side, things like being told by their provider that their viral load was undetectable was said to motivate them to remain adherent to their medications.

Provider: That's another thing that we do. We celebrate when they come. "I'm glad you came . . . Yeah, and whether or not you're taking your medicine, I'm glad you came so they always feel – [#03]

Patient: It's getting better cos like my CD4 count is up there. The last time I done it I think it was about ---- and then I was undetectable. And that's very good. [#06]

Provider-patient communication: There was also concordance between patients and providers on providers communicating at an appropriate health literacy level. According to some of the care providers, the majority of patients in the target population are not highly educated, and many are unable to read or write. They reportedly were uncomfortable with disclosing their illiteracy and some patients tended to acknowledge that they understood the information being given them when in actual fact they may not.

Provider: I'm always afraid that there's people that come out of doctor's visits anywhere that they say they understand but as soon as they step outside the door. [Provider #13]

The "read-back" strategy was recommended to ensure patients' comprehension of information. From patients' perspective, communicating at their literacy level was also advocated. One of the patients interviewed termed it "street knowledge" implying common everyday English used by the lay person on the 'street' and not medical terminology.

Provider: I think there's a component—you know there's one thing that I think as far as helping is concerned, if when people are training and going in and talking to people about taking their medications, like we've got to— "Okay, you tell me what I just told you." Feed back to me. I just did that this morning with one person . . . I said, "Let's go over that again." I think having them reiterate—I can sometimes talk until I'm blue in the face and jumble up my words, depending upon how fast I'm talking or what have you. It's like, "Okay, tell me what you need to do." I think if we could do that more often that might help people to be able to understand what's going on. [Provider#13 - *recommendation*]

Patient: I go on the computer . . . online, and I read up on my medications. And if I don't understand it, I take it to someone who can break it down for me to understand it, because the words that the doctors use – you really don't know what they are saying or what it means. And me I'm not what you would say emm a medical doctor, but if you will tell me in a way, I would say "street knowledge" . . . [Patient #07]

Instrumental support – patient education and counseling: This to some providers was the key to patient medication adherence. There was a lot of advocacy in their narratives for continued patient education and adherence counseling. Patients' interviews also reflected the impact of this provider role in changing disease and treatment perception and therefore enhancing medication adherence. Another form of instrumental support discussed was the provision of reminder tools such as alarms and pill-boxes which have been previously discussed.

Provider: Constant education [perceived role]. “This is why you need to take this medication. This is what you need to do with it.” Talking about the mutations and why it’s so important for them to keep the medications routinely being given rather than skipping doses. [#13]

Patient: Well my health care provider sat me down and talked to me about it – the good and the bad. She told me that if I don’t take it what could happen and if I do take it what could happen. I made up in my mind that I didn’t want to go down that road of being bad. I wanted to have a good health, and so far my health is good if you come down to my HIV. [#07]

Current Practice versus Provider Perceived Patient Needs

The fourth objective of this study was to identify gaps between current care practices and what was care providers perceived as effective in meeting the needs of patients in the target population. There were some current practices in the HIV care process that were perceived as being more detrimental than beneficial to persons in the target population. These included –

1. Immediate/urgent efforts to link patients to care;
2. Excessive paperwork;
3. Restrictive medication-related policies: example – medication cut-offs for defaults in ADAP [Aids Drug Assistance Program];
4. Generalized versus individualized care related policies; and
5. Inefficient dispensing of antiretroviral medications.

Immediate/urgent efforts to link patients to care: Active referral, though more effective than passive referral in linking people to care, it was perceived as being too quickly implemented in the process of care. The current practice of having a patient just diagnosed with HIV immediately initiate contact with agencies that provide financial assistance and facilitate the care process was not always successful in linking people to care. Providers were concerned about the timeliness of these efforts since they were made at a time when the patient was still processing the news of their diagnosis. From the narratives, both care providers and patients agreed that the moment following diagnosis may not be the best time to try to get them into care. There were suggestions

that focus should be more on counseling the patient and getting her to a place where she could be more receptive to the information being provided versus trying to immediately enroll the person in care.

Provider: "You need to call them." Then, they pick up the phone while they're sitting in the office and call. That point in time is not the best time for that person to call. They're not ready. They're processing, "Oh, my goodness. I've just been told I'm HIV-positive. What am I gonna do now? Oh, who's this person I need to talk to? Why do I need to call them?" I get that a lot. "I don't know why I'm calling you, but I have to call you. They told me I need to call you." . . . I feel like they get so much information when they're first diagnosed that, one, they're overwhelmed with their diagnosis, [cross talk 31:11] two, they're overwhelmed with the information that's given to them and even scared. [provider #10]

Patient: And they said well "(her name) we need to talk to you". And I was like OK. They said "Well we have something to tell you em so your tests came back and we checked you for virus and it came back positive." And I kind of went into a phase of like when you hear Charlie Brown go "whaaaa whaaa whaaa!" You know I'm not really hearing these people. And so they asked me how I felt about the whole thing. And you know at that moment I was like numb. I was like I heard it and I didn't hear it. [Patient #01]

Recommendation: Providers recommended that following diagnosis, patients should be counseled and allowed some time to come to terms with their status before actively engaging them in the process of enrolment into treatment unless their health status was very severe and required immediate treatment.

Provider: They need to be told they're HIV-positive and a counselor right there with them to talk through or bring a family member with you that you're really comfortable with . . . so they're not in this room, sitting there by themselves, given this diagnosis shocked and, "Oh, my gosh. What am I thinking now?" They need a little bit of time to process that. Let 'em go home after they speak to a counselor or whatever. Come back. Call 'em back the next day. "How are you doing? What's going on?" Maybe two days later, call 'em back and say, "Okay. We need to get you into care. This is really important." The thing is, HRSA, we have a lot of really strict guidelines now about getting newly diagnosed people into care super quickly. [Provider #08]

Excessive paperwork: To obtain financial assistance for healthcare, PLWHIV were required to meet certain eligibility criteria based on income level, family composition and employment status. Majority of persons in the target population were usually eligible for these services. However they were required to re-certify their eligibility every 6 months. This re-certification process involved filling out paper work and returning same in a timely manner to maintain continuity of care. While some patients in this population were good with doing this, some others had difficulties keeping up with this requirement.

Some of the issues included

- i. Not receiving the forms because of frequent movement from one place of residence to another;
- ii. Difficulty filling the forms due to literacy problems (case manager would usually help out those who could not read or write but it was still a cumbersome task for the client); and
- iii. Simply forgetting because of other priorities in their lives - especially care-giver responsibilities and financial burdens.

Provider: It slows the process down in my opinion. I have to keep my mouth shut about that. I don't see where adding an extra layer of unnecessary paperwork to people who are already overburdened and many of them are illiterate, or not very literate, and don't understand forms, and stuff, is improving their quality of services, or is improving their getting any healthcare. I don't see it. That's the one thing I'd change. I'd cut that out . . . It bugs me, bugs me. I do not see it as a benefit. Of course, they're all hung up on it because some big wig in state decided this was gonna be such a wonderful thing. My attitude is how is extra paperwork and slowing the process down where I can't even go and see a client unless I got your okay and you don't know what I'm doing, and you're giving 'em the wrong information, gonna help my clients. Now you've added layers of paperwork to what I have to do, which again keeps me from taking care of my clients.[Provider #06]

The point made by care providers is that six month re-certification was not necessary since the economic context of most members of this population did not tend

to change much if all. Recommendation is that the re-certification be done annually and the number of forms reduced.

Provider: We've discussed changing the re-determination for eligibility to every year from every six months. Their argument is, "Well, food stamps is every six months, so they can do it at the same time." Well, it's not always at the same time [laughter] their food stamps is. For a lot of our clients that are low income and have food stamps, if they provide proof of food stamps, then that waives a lot of the information that we have to get from them regarding their income. If they maintain their food stamps, which sometimes doesn't happen but for the majority they do, because that's a really needed service. . . . I feel like if we did it once every year, it might help. Then, it also might—we might get a backlash of, "Oh, it's only every year now? Now, I really forget." You know? [Provider #10]

Restrictive policies: To continue to receive drugs paid for by ADAP, patients were required to strictly keep up with their follow-up clinic visits and laboratory tests. In addition, they were under perpetual threat of having their medication cut off if they missed picking up their refills. One of the care providers suggested that patients be given multiple chances and receive continuous patient education and counseling to help them understand the importance of medication adherence rather than cutting off their medication supply. Suspending dispensing of medication was viewed as sending mixed messages to patients since it seemed to contradict the core purpose of the medication counseling medication. It was thought to undermine the whole message around the importance of medication adherence.

Provider: I think we're spending way too much time making people jump through hoops to get their medicine or to do this or that. I think it's affecting them being able to their medicine. I think it's affecting their attitude about how we take care of them and all of that and I think it just creates problems right and left. I don't mind the general idea of, "No, you gotta be seein' the doctor and gettin' your lab tests and followin' through to keep getting your ADAP medicine or to make sure you still have your Medicaid." I don't have a problem with that. It's this cutting off of medication because they missed or they didn't meet the deadline . . . You gotta give 'em five chances. You gotta give 'em five other chances and you gotta help 'em make sure that

they realize that or get that because if you don't, you're only causin' trouble and it's not a good trouble. It's bad trouble. It does frustrate patients. It upsets them and that comes out in other ways like, "I'm not gonna listen cuz "it doesn't make any sense. They don't really care about me so why should I take this medicine?" It comes out in lots of different ways. [Provider #17]

Generalized versus individualized care-related policies - Some providers viewed some of the policies as not being patient-centered and the care protocol as being insufficient in their flexibility to accommodate specific needs of patients. When strictly implemented, some rules were viewed as doing more harm than good for individual patients.

Provider: The medical system in general is a horrendous system. It's not patient-friendly. It's never patient-friendly . . . the system just does not make it easy at all. There's always a rule about why they can or can't do something and I get it that we need rules, but it's without ever considering what is goin' on for the individual, right? That if there's a rule, there's gotta be an exception. I mean that's my belief [chuckle]. As a system it's pretty bad. [Provider #17]

The recommendation was that much as rules were necessary, room should be made for exceptions with the larger objective of achieving better health outcomes for this population.

Provider: I think pharmacy is just now getting there to the point where I can call a doctor and be, like, "It's just not happening. I know you want her to take one twice a day, but she's not doin' it. It's not gonna happen, so find another way because telling her and then watching her not do it is pointless." . . . I think with women I'm giving them—listening to what is the barrier I think is key. Yeah. "Why is it that you don't wanna do it?" Being honest and making it very clear, "I'm gonna try to find another way? What is it about this way that you don't like? What is it about this drug that doesn't make it happen?" rather than just watching someone decline and then yelling at them about it cuz I think that a lot of times women—if it doesn't work out, they just don't do it. [Provider #20]

Inefficient dispensing of antiretroviral medications: A care process that was considered harmful was the partial dispensing of an antiretroviral regimen consisting of

more than one drug. A care provider described an undesirable practice of giving a patient some of the drugs prescribed and asking them to come back for the other(s) because it was out-of-stock

Provider: We have pharmacies who will give patients two out of their three antiretrovirals and tell 'em, "You gotta come back next week. We don't have this one." [Provider 17]

Provider: A lot of times, they come in and get one, and two, we're out of stock. They gotta come back. We try to make sure that that doesn't happen. [Provider #20]

. The recommendation was that sufficient pills be given to at least cover the period the patient has to wait before getting the complete refill.

Provider: It's like, "Eeeenh! Time out." You stop and you say, "How many pills of each one do you have?" Maybe you should even call 'em up and ask 'em to bring in their pill bottles so you can see what they've got. If you need to—I don't care what insurance says—give 'em ten of these pills so they can come back the next week to do this cuz you're gonna count out those ten pills from the next bottle anyhow Ya know, but what's the big deal? You know they've gotta come back. They've been comin' back. If they've come to you before, fine. They're gonna come back. [Provider #17 - *recommendation*]

Another issue with medication was policies about replacing lost medication.

Reportedly, getting medications to replace legitimately lost pills was very difficult as current policies did not allow for such augmentation separate from the usual refill.

Provider: An average HIV regimen's about three grand a month. It's not cheap. You and I both pay for it, but we're not perfect and sometimes people legitimately lose their drugs. Either you leave it on the subway or as someone happened yesterday, she left it in her car and it got stolen. Well, in New York if I had that happen to me, I would call Medicaid and say, "Look, has this patient ever lost medicine before?" and they say no, so I can put like a seven in their computer, hand it out, and then give it to them. Down in Florida, forget about it. If you get a police report and you gotta prove it, and by that time, the damage will be done . . . Yesterday I was able to fortunately, the time that she lost it, I still could fill it but it was really a nightmare. See, I think it's harder down here. [Provider#11]

Other recommendations from care providers included peer education/ navigation and patient advisory groups.

Peer education & peer navigation: Many of the care providers were not knowledgeable about the role of peer navigators in HIV care. Some of the providers were aware that such services existed but did not have a first-hand experience of how this service worked or the benefits to persons living with HIV. However, they acknowledged (and some recommended) that having persons living with HIV included in the process of care would be beneficial especially for this population.

Provider: I just found out in another conference that there are peers who have HIV—volunteers who are willing to talk, and I think we have to make more use of them. I didn't even know . . . [Provider #19]

Patient: I think that if you connect someone positive to a person that's positive, and someone that's positive and really taking their medications, and they are doing positive things first of all, that will kinda take the stigma away because you feel so alone when they first tell you that you're positive. It's like 'God' and you might go to that Charlie Brown state of like "whaa whaaa whaa, I don't wanna hear you". [Patient #01]

Patient Advisory Groups: One of the providers shared an experience that she said enhanced her understanding of the needs of PLWHIV. It was attending 'patient panels' where PLWHIV were asked to share with the providers their experiences, concerns and needs. Having such panels where patients became the 'experts' and gave providers some insight into their needs and the assessment of the care being given to them was thought to be potentially useful in evaluating quality of care.

Provider: They bring panels of HIV patients just for us to hear their stories: What would you like us to do? What's the worst interaction you ever had? What's the best interaction you ever had at any pharmacy? . . . —just to give us an idea of if it is appreciated, cuz we don't get to hear that from our patients all the time. That we feel it's a service worth specializing, cuz you can't sell what you don't believe in . . . We do that twice a year. We go

down. They bring different panels. Some of the patients are repeat patients, and we know them. [Provider #20]

Summary of Findings

A conceptual model was developed using the data collected from the interviews conducted with health care providers. The model was similar to the model developed from patients' perceptions in the preliminary study in terms of the basic categories and components that interact to influence linkage to care and medication adherence in the target population. The differences lay mostly in the specific issues identified within each category and the perception of how some of the sub-categories (or themes) were related. For example though there were similarities in provider and patient perceptions of the phases of the patient illness experience (Figures 4-1 and 4-2, also Tables 4-10 and 4-11) there were subtle differences in how patients transitioned through those phases.

A key difference was the inclusion of the socio-economic context of the patient in the conceptual model of provider perceptions. The socio-economic circumstance of patients in the target population was perceived by providers as underlying most of the factors considered as barriers to care and medication adherence in the target population.

From the patients' perspective, the trajectory of the illness experience appears to be a more linear process with patients progressing from the initial phase of denial to a state of acceptance of their HIV status. Patients then reportedly went on to perceiving themselves as having control over the disease. This was usually as a result of increased knowledge or a sense of empowerment that came with disclosing their HIV status to other people and/or being open about it. Then there was the point of

realization that their lives had some purpose and that they were in some way relevant to others. From the provider perspective, the illness experience was viewed slightly differently in that patients were seen as going from denial to acceptance but the points of perceived control and self-disclosure were perceived as probable but not necessarily routes to the point where patients were perceived as being motivated to stay in care and take their medications.

With respect to patient characteristics, mental health issues were identified by care providers as having significant effect on patient care considering the impact on cognitive function; thereby limiting patients' ability to engage in self-management of disease. From the provider perspective, mental health was associated with domestic violence, physical/ sexual abuse, and substance abuse as an addiction. On the other hand, patient participants talked about depression mostly in association with denial and its role in medication adherence, but other psychiatric conditions were not mentioned. Substance abuse was also used as a coping mechanism by some persons versus being strictly a pre HIV diagnosis addiction.

Other patient-related factors that drew contrasting perspectives were faith in God and characteristics of the medication regimen. Faith in God while acknowledged as a factor in patient wellbeing was not regarded by providers in the context of enhancing self-efficacy in behavior change. Different characteristics of the regimen were identified by providers and patients respectively. While providers cited the complexity of the regimen as a barrier, patients were more concerned with chronic medication use and reported a sense of being overwhelmed by the notion of a never ending regimen.

For health care system and provider related factors, care providers interviewed touched on all the areas that patient participants considered important or of influence in their health related behavior and also identified transportation as a major barrier. Providers were also considerably knowledgeable about aspects of care and approaches that were important to and preferred in this patient population.

Gaps in current practices that were thought to affect patients in this population were mostly policies that did not make accommodation for unique patient challenges, including literacy and unstable housing. Peer navigation, utilization of patient advisory groups (PAGs), and the “teach back” communication technique were recommended as potentially effective intervention strategies to enhance medication adherence in this population alongside making policies more patient-centered.

In general, while patients’ perceptions were limited to their unique experiences as individuals, care providers had a broader perspective of barriers and facilitators of medication adherence in this population and could make distinctions between subgroups within the target population. Therefore, some factors identified were more specific to some subgroups of patients while not necessarily applicable to all.

Table 4-1. Summary of provider participants' demographic characteristics

Professional Discipline	Number
- Nurse Practitioner/Registered Nurse	3
- Pharmacist	3
- Physician	8
- Public Health Professional	1
- Social Worker	5
- Community Health Worker	1
Primary Functional role in HIV care	
- Clinician	10
- Nurse	2
- Case Manager	7
- Pharmacist	2
Primary employment setting*	
- State/Local Health Department	7
- Academic Health Center	8
- Private Practice	3
- Not-for-profit Organization	8
- Specialty Pharmacy	1
- Retail Pharmacy	1
- Outreach clinics	1
Care site location**	
- Rural	14
- Suburban	19
- Urban	9
Gender	
- Male	7
- Female	14
Racial/Ethnic group (self-identified)	
- Caucasian (non-Hispanic)	16
- Asian/Asian American (non-Hispanic)	3
- Latino/Hispanic (White)	2
Age Category	
- < 30years	1
- 30 – 39 years	8
- 40 -49 years	1
- 50 – 59 years	3
- 60 – 69 years	8

*Some care providers are employed by multiple agencies

** Some providers work in more than one care setting

Table 4-2. Category 1: Socio-economic context – themes and summary of perceptions

- A. Income Level
- B. Care-giver role/Financial responsibility
- C. Instability
 - Job
 - Relationship
 - Housing
 - Incarceration
- D. Education/ literacy
- E. Lifestyle
 - High risk sexual behavior [multiple partners, unprotected sex]
 - Substance abuse [alcohol, illicit drugs]
- F. Domestic violence/ sexual abuse
- G. Life-changing traumatic event

Participants' perceptions on the influence of patients' socio-economic context

- The social context and economic burden borne by members of the target population reportedly makes them more vulnerable to certain lifestyles, employment conditions, living circumstances and abusive situations; all of which present barriers to HIV care and medication adherence.
 - Less education/ lower literacy level appears to be correlated with cognitive ability (in understanding HIV disease and treatment); and is associated with poor adherence regardless of race/ethnicity.
 - Persons who are more educated and have good jobs (earned higher income) appear to have a better understanding of the disease and treatment, have better coping skills and are therefore more likely to be adherent to their medication.
 - African American women living with HIV however were more likely than not to be in the lower income stratum and have low educational attainment/ literacy level. Persons in the target population commonly bore the financial and care-giver responsibilities in their families. These responsibilities took priority over their self-care of HIV disease.
 - In the target population, instability [relationship, job, incarceration, and especially housing] was perceived to be a significant barrier to medication adherence.
 - Substance abuse was thought to be more prevalent in a sub-group (usually younger patients) of the target population and therefore was not considered a significant barrier in the general target population.
 - Traumatic life-changing events like the death of a loved one was observed to impact adherence behavior negatively.
-

Table 4-3. Category 2: Patient illness experience - themes and summary of perceptions

- A. Denial
 - 1. At diagnosis
 - 2. Asymptomatic
 - 3. Undetectable viral load
- B. Acceptance
 - 4. HIV knowledge/understanding
 - 5. Faith in God
- C. Perceived Control of Disease
 - 6. Perceived efficacy of treatment
 - 7. Clinical Outcomes [CD4 count, viral load]
- D. Disclosure
- E. Motivation
 - 8. HIV knowledge
 - 9. Maintenance of a simple regimen
 - 10. To see their children grow up
 - 11. Care-giving responsibility [children, elderly]
 - 12. Perceived efficacy of treatment
 - 13. Deteriorating health/ 'near death' experience
 - 14. Faith in God/ spiritual encounter

Participants' perceptions on the patient illness experience

- Denial is a common experience immediately following diagnosis of HIV. Persons in denial are unlikely to follow through with linkage to HIV care and/ or adherence to treatment regimen.
- Denial and acceptance of status are not necessarily static states – persons may fall back into denial when they become asymptomatic or their viral load becomes undetectable especially if they have a poor understanding of HIV disease.
- Denial and medication adherence are not necessarily mutually exclusive. Some persons in the target population may take their medication and still be in denial.
- Denial is more common among persons who did not expect to be infected with HIV; persons who engage in risky sexual behavior seem less in denial and more accepting of their diagnosis, but do not necessarily perceive themselves as having control of the disease.
- Acceptance of HIV status usually occurs over time, which period varies from person to person and is associated with change in disease perception.
- Persons who have accepted their status are more likely to stay in care and take their medication.

Table 4-3. Continued

Participants' perceptions on the patient illness experience

- With the acceptance of the diagnosis, persons in this population are more likely to disclose their status to someone else and therefore have more social support available to facilitate self-care.
 - Perceived control of disease is thought to be a function of adequate knowledge and understanding of HIV disease and treatment resulting from continuing patient education.
 - Perceived control is reinforced by efficacy of treatment and the experience of positive health outcomes (no sick days, no hospitalizations, etc.).
 - Persons who stay adherent to their prescribed treatment, usually have some motivation to do so (eg. children and care-giver responsibility to elderly relatives).
 - Providers facilitate medication adherence in this population by determining potential motivating factors per individual and “pitching” these to them.
-

Table 4-4. Category 3: Mental and emotional health - themes and summary of perceptions

- A. Psychiatric Disorders
 - Untreated pre-existing conditions
 - HIV disease progression
- B. Depression
 - HIV-related
 - Pre-existing
- C. Emotional Distress
 - Anxiety, Shame, Guilt,
- D. Living in fear
 - Disclosure/Exposure of status
 - Being Ostracized/Abandoned
 - Stigma/Discrimination

Etiology:

- Substance abuse
- Physical/sexual abuse
- HIV diagnosis

Participants' perception on mental and emotional health

- Mental health issues are perceived to be prevalent in a sub-group of the target population and thought to pose significant threat to medication adherence.
 - Psychiatric disorders are perceived as being associated with substance abuse and history of physical and/or sexual abuse at both childhood and adulthood in this population. Prior to HIV diagnosis, these are often untreated.
 - Mental health illnesses (including depression) are also commonly associated with HIV diagnosis and outcomes of HIV disease progression in this population.
 - Mental health services even where available may be under-utilized because of the stigma associated with mental health illness.
-

Table 4-5. Category 4: Support – sub-categories, themes and summary of perceptions

A. Social Support [Emotional]

- Family
- Church

B. Instrumental Support

- Healthcare providers
- Supportive services (housing, transportation)
- Assistance programs (Ryan White → case management, counseling; ADAP, Pharmaceutical companies → payment for antiretroviral drugs)

C. Peer Support [Affiliational support]

- Peer navigation
- Support group

Participants' perceptions on the role of support

- Having some form of support is perceived as significant in facilitating adherence to antiretroviral treatment in the target population.
 - Information, tools and assistance provided by healthcare professionals and support services may be more distal with regards to influencing care-seeking and medication taking behaviors.
 - Support at home or from within one's immediate social network is perceived as being more proximate in terms of facilitating adherence in this population.
 - Social support is contingent on self-disclosure of HIV status. Generally, members of the target population are hesitant to disclose their status and therefore tend to lack the needed support. However, they usually receive support (from family) when they disclose their status.
 - Support from other persons living with HIV (PLWHIVs) may be pivotal in changing adherence behavior as members of the target population may be more receptive to counsel from persons who they perceived to be able to identify with their specific illness experience.
 - Including PLWHIVs in the care process can make navigating the health care system much easier for newly diagnosed patients from this population.
 - Interaction at support groups may provide some premise for engaging in vicarious conditioning (observational learning) with regards to care-seeking and adherence behavior.
-

Table 4-6. Category 5: Access to care – themes and summary of perceptions

A. Availability of health care services

- Rural versus urban
- Under-utilization [Stigma, lack of information]

B. Affordability of health care services

- Insurance coverage
- Financial assistance

C. Accessibility to healthcare facilities

- Transportation
 - a. Availability
 - b. Under-utilization [Stigma, Waiting time, Co-ordination]

Participants' perceptions on access to care

- A considerable proportion of the target population (likely a function of SES) is resident in rural and semi-rural areas where there are limited resources (particularly public transportation) and fewer HIV care-related services (eg. mental health, substance abuse rehabilitation).
 - Relevant services where available may not be accessible to persons who do not have the necessary insurance coverage and/or are not eligible for assistance programs that pay for or provide those services.
 - Services may be under-utilized because patients are unaware of these services (eg. private practice settings that undertake care for the uninsured, assistance programs that undertake payment for relevant care, social security bus) or because patients are unwilling to access them because of perceived stigma (mental health services, Medicaid bus).
-

Table 4-7. Category 6: The healthcare system – themes and summary of perceptions

A. Complexity and Inefficiency of the care process	<ul style="list-style-type: none"> • Excessive paperwork • Restrictive policies <ul style="list-style-type: none"> - Eligibility re-certification - Insurance/billing - Medication dispensing - Enrolment into care (<i>waiting list; retention policy</i>) • Passive referral
B. Fragmentation of the System	<ul style="list-style-type: none"> - Co-ordination of care (<i>co-morbidities, type of insurance</i>) - Integration (<i>care providers accessing records, information on con-concurrent treatments</i>)
C. Characteristics of the Care Setting	<ul style="list-style-type: none"> - Privacy - Consistency of the care provider - Waiting time/Face-time with care provider
D. Resources	<ul style="list-style-type: none"> - Availability - Allocation

Participants' perceptions on the healthcare system and medication adherence

- In providing care to persons living with HIV (PLWHIV), the healthcare system is perceived as being considerably focused on cost-savings but relatively effective in linking persons who are newly diagnosed to care services.
 - The policies (especially for eligibility and referral), the care process and the way care is structured are perceived as not sufficiently "patient-centered" in retaining patients in care and facilitating adherence (with follow –up visits and medication) for sub-groups of persons in the target population.
 - The paperwork involved in the process of care for persons living with HIV is perceived as excessive and often overwhelming for members of the target population who are uneducated and/or have low literacy levels.
 - Some policies are perceived as being more restrictive than inclusive with respect to engaging and keeping persons in care and enhancing medication adherence in this population. Policies that cut off medical care services (for example medication refills) are thought to send "mixed messages" to patients about the necessity of medication adherence to their health outcome.
 - The fragmented structure of care interferes with continuity and/or comprehensiveness of care especially for persons in the target population who receive care from multiple providers; with consequent impact on medication adherence.
 - Care-settings that are perceived by the patient as not providing adequate privacy and patients' experiences of long waiting times during clinic visits can be significant barriers; which may result in loss to follow-up.
 - Persons in the target population are more likely to stay in care and be adherent when a relationship with their care provider is established. Building a provider-patient relationship is more easily facilitated by having a consistent care provider and sufficient interaction per clinic visit.
 - In addition to resources being very limited in this local setting, there are beliefs that these may not be efficiently allocated for the best care outcomes.
-

Table 4-8. Category 7: Provider-patient interaction –themes and summary of perceptions

A. Provider-Patient Relationship

- Accessibility
- Knowledge [of patient]
- Rapport
- Trust
- Care/Commitment

B. Care Approach

- Holistic
- Patient-centered [Individualized, Patient preference, Patient participation in decision –making, accommodation, appropriate timing, negotiating, etc.]
- Addressing problems/offering solutions [empathy/ sympathy, eliciting information]
- Time investment
- Incremental goal-setting
- Collaborative effort
- Vicarious conditioning
- Treating patient as a person [Physical touch, Respect]
- Positive reinforcement

C. Provider-Patient Communication

- Non-judgmental attitude
- Active listening

Participants' perceptions on the influence of the provider-patient interaction

- The key characteristic of the relationship with the patient is the provider's demonstration of care and commitment to the patient's well-being.
 - Other features of the provider-patient relationship perceived to be important to the target population and therefore contributory to enhancing care-seeking and adherence behavior include -
 - i. Being readily accessible both at the care site and outside clinic hours;
 - ii. Developing a personal relationship so that care can be tailored to meet patient-specific needs;
 - iii. Building rapport with patient so that that they feel comfortable enough to participate in their care [ask questions, give information that may be relevant to their care, etc.];
 - iv. Building trust – historical and personal experience of the healthcare system has led to some level of mistrust. Patients also need to perceive their care provider as knowledgeable and competent in managing them.
-

Table 4-8. Continued

Participants' perceptions on the influence of the provider-patient interaction

Given [the complexity of] their socio-economic context, the care approach that will be most effective in achieving desired outcomes needs to take into account non-medical aspects and therefore should be holistic and patient-centered rather than disease-centered. With regards to care approach, the following perceptions were identified from the data analysis.

- It is important to this population that they perceive themselves as being treated with respect and acknowledged as autonomous individuals as opposed to feeling like they are being treated as just another patient.
 - Care for some members of this population may be more time-intensive than for the average patient living with HIV. Time is needed to establish a relationship, build trust, educate and counsel.
 - Effective communication skills can help identify patient needs and levers (motivating factors) that can be “pulled” to facilitate adherence. Key skills include active listening and motivational interviewing.
 - Focusing on small inter-mediate goals may achieve more results. For desirable lifestyle changes (substance abuse, prostitution) total abstinence may not be an attainable goal, therefore “harm reduction” may be more achievable and more receptive to the patient.
 - Communication and collaboration among all care providers seeing a patient are helpful in coordinating care for this population and ensuring that problems are identified and adequately addressed.
 - Talking to persons in this population about the success stories of other patients may motivate them to pattern their behavior after the examples – a sort of vicarious learning by proxy.
 - Communication from the care-provider needs to be perceived as non-judgmental.
 - Celebrating small successes such as making it for a follow-up visit, when celebrated serves as positive reinforcement and could enhance adherence in this population.
-

Table 4-9. Category 8: Patient characteristics – themes and summary of perceptions

A. Patient Knowledge & Understanding

- HIV knowledge [prior to diagnosis]
- Patient education/counseling
- Cognitive ability

B. Patient Disease/Treatment Perception

- Normative beliefs
- Patient education/counseling
- Medication-related experience [side effects; perceived efficacy]

C. Patient Responsibility/Self-Management

- Patient participation in care [passive vs. active involvement]
- Dependence on care-giver [cognitive , functional ability]
- Maturity [Age] → coping

D. Self-efficacy

- Lifestyle change [motivation, maturity]
- Medication adherence [complexity of regimen, side effects]

Participants' perceptions of patient characteristics that influence adherence

- Most persons in the target population have little or no knowledge of HIV at the time of diagnosis. Perception of HIV disease and antiretroviral treatment is often shaped by misconceptions rooted in normative beliefs and reinforced by invalid information from sources outside the healthcare system such as relatives and friends.
 - Patients' perception of HIV disease and/or treatment is perceived as significantly influencing adherence behavior.
 - With continuing patient education/ counseling, patients' increasing knowledge and understanding of HIV may lead to change in perception of HIV disease and/or treatment; resulting in better adherence to prescribed regimen.
 - HIV knowledge alone is not always sufficient to motivate most patients in the target group to adhere to their prescribed regimen – some patients who are assessed as being knowledgeable are still found to be non-adherent. Non-adherence in these cases may be attributable to other barriers.
 - In a subset of the target population, patient education does not appear to increase HIV knowledge or change adherence behavior. Persons in this subgroup are thought to have low cognitive function that may limit their ability to adequately process and understand the information provided. Self-management may not be effective in achieving desired health outcomes. Adherence in this subgroup is more likely if a care-giver (who understands the impact of antiretroviral treatment on HIV disease) undertakes responsibility for their care.
-

Table 4-9. Continued

Participants' perceptions of patient characteristics that influence adherence

- The experience of side effects in the absence of adequate patient education may foster patients' beliefs that antiretroviral treatment is more detrimental to health than beneficial.
 - Persons who take responsibility for their care are more likely to actively participate in their care process [pro-active in monitoring progress, asking questions, involved in decision-making] and tend to be more compliant in taking their prescribed medications.
 - Persons who are more educated and have more stability in their lives (steady income, housing) are more likely to take responsibility for their care.
 - Older persons in the target population are also more likely to take responsibility for their care compared to younger patients who tend to be more dependent on a care-giver.
 - Persons who had some motivation were more likely to have the self-efficacy to make changes that enhanced adherence behavior. Maturity was associated with self-efficacy in this population.
 - Simpler regimen was also associated with increased self-efficacy.
 - Some patients (in spite of continued education and motivation) simply did not have the self-efficacy to take their medications.
-

Table 4-10. Summary of comparative analysis: patient and provider perspectives

Contrasting perceptions

Patients' Illness Experience

- a. Dynamics of the transition from states of denial to acceptance
- b. Necessity of perceived control of HIV disease
- c. Motivation for adherence versus finding purpose/relevance

Patient Characteristics

- a. Substance abuse as an addiction versus substance abuse as a coping mechanism
- b. Modeling' as key to change in disease/ treatment perception
- c. The etiology of mental health problems
- d. Cognitive ability related to self-management
- e. Faith in God as a facilitator of self-efficacy
- f. Complexity of regimen versus chronic administration as a significant barrier
- g. Perceived significance versus actual experience of peer support in HIV care

The Healthcare System

- a. Access to care
 - Transportation
- b. Healthcare process
 - Restrictive policies
 - Excessive paperwork
- c. Healthcare structure
 - Fragmentation
 - Privacy in care settings

Provider-related Factors

- Provider-patient communication
- Information overload
 - Redundancy of information
 - Language barrier

Socio-economic Context

- a. Income level
 - b. Care-giver role/ financial responsibility
 - c. Instability – (*particularly housing*)
 - d. Education/literacy
 - e. Lifestyle
 - f. Domestic violence/ sexual abuse
 - g. Life-changing traumatic event
-

Table 4-10. Continued

Similar perceptions

Patient illness experience - Different phases following HIV diagnosis

- a. Denial
- b. Acceptance of HIV status
- c. Perceived control of HIV disease
- d. Self-disclosure of HIV status
- e. Motivation (*provider*)/ Finding purpose/relevance (*patient*)

Patient characteristics

- a. Patients' disease/treatment perception
- b. Medication-related experience (*side-effects*)
- c. Patient responsibility/ self-management (*passive patient role*)
- d. Perceived social support
- e. Perceived peer support
- f. Self-efficacy to make lifestyle changes

The healthcare system

- Access to care - Lack of knowledge of available services
- Healthcare Process - Active vs. passive referral
- Healthcare structure – consistency of healthcare provider

Care-provider related factors

- a. Provider-patient relationship
 - Accessibility
 - Care and commitment
 - Personal patient knowledge
 - Building trust
 - b. Provider care approach
 - Non-judgmental attitude
 - Treating patient as a person
 - Holistic care
 - Physical touch
 - Positive re-enforcement
 - c. Provider-patient communication
 - Appropriate health literacy level
 - d. Instrumental support
 - Patient education and counseling
 - Adherence tools (pill boxes, alarms, reminders)
-

Table 4-11. Summary of care providers' recommendations

Current practice	Recommendations
Immediate/Urgent efforts to link patients to care	<ul style="list-style-type: none"> • Assessment of patient's emotional state • Address patient's immediate concerns • Adequate counseling over time
Excessive paperwork [6 monthly re-certification to maintain eligibility for aid]	<ul style="list-style-type: none"> • Annual re-certification • Fewer forms to fill
Restrictive policies [medication cut-offs for defaults in ADAP]	<ul style="list-style-type: none"> • Identify patients' challenges • Offer solutions/ suggestions [using motivational interviewing] • Continue patient education to increase patient knowledge and understanding
Care related policies/protocol that are not patient-centered	<ul style="list-style-type: none"> • More flexibility in implementing policies and protocols • Prioritize tailoring care process to meet patient needs and preferences rather than adherence to policies/protocol
Policies about dispensing of antiretroviral medications <ul style="list-style-type: none"> - Partial dispensing of antiretroviral regimen - Non-replacement of lost medications 	<ul style="list-style-type: none"> • Dispense enough pills to 'tide' the patient over while stock is replenished • Ensure that medication is always in stock • Replace lost medications especially for a one-time occurrence •
Other recommendations <ul style="list-style-type: none"> • Peer education and peer navigation as part of HIV protocol of care • Implementation of Patient Advisory Groups [PAGs] • Read-back/Teach back in patient communication 	

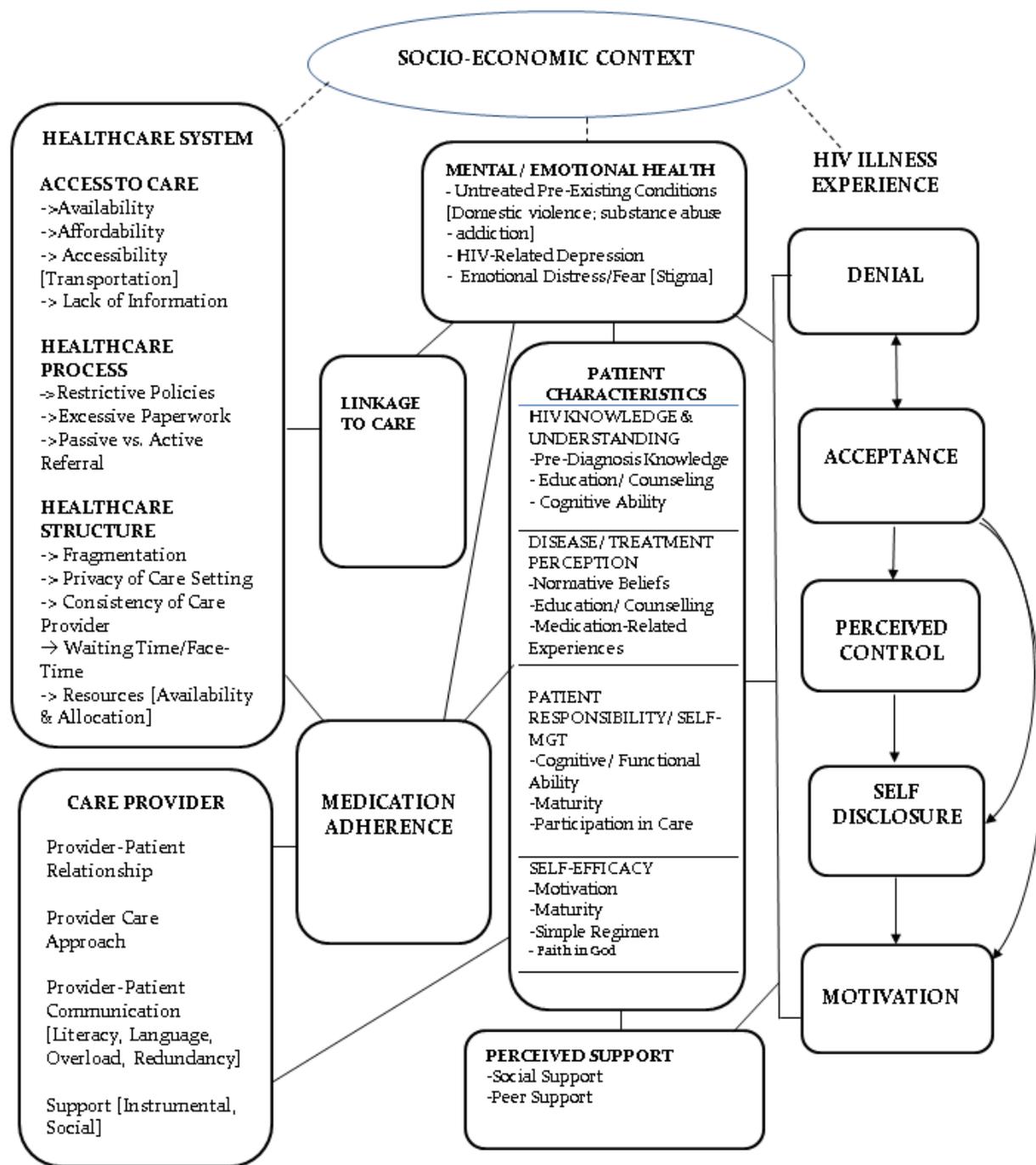


Figure 4-1. Conceptual model: Care-provider perceptions of care-seeking & adherence behavior among African American women living with HIV/AIDS

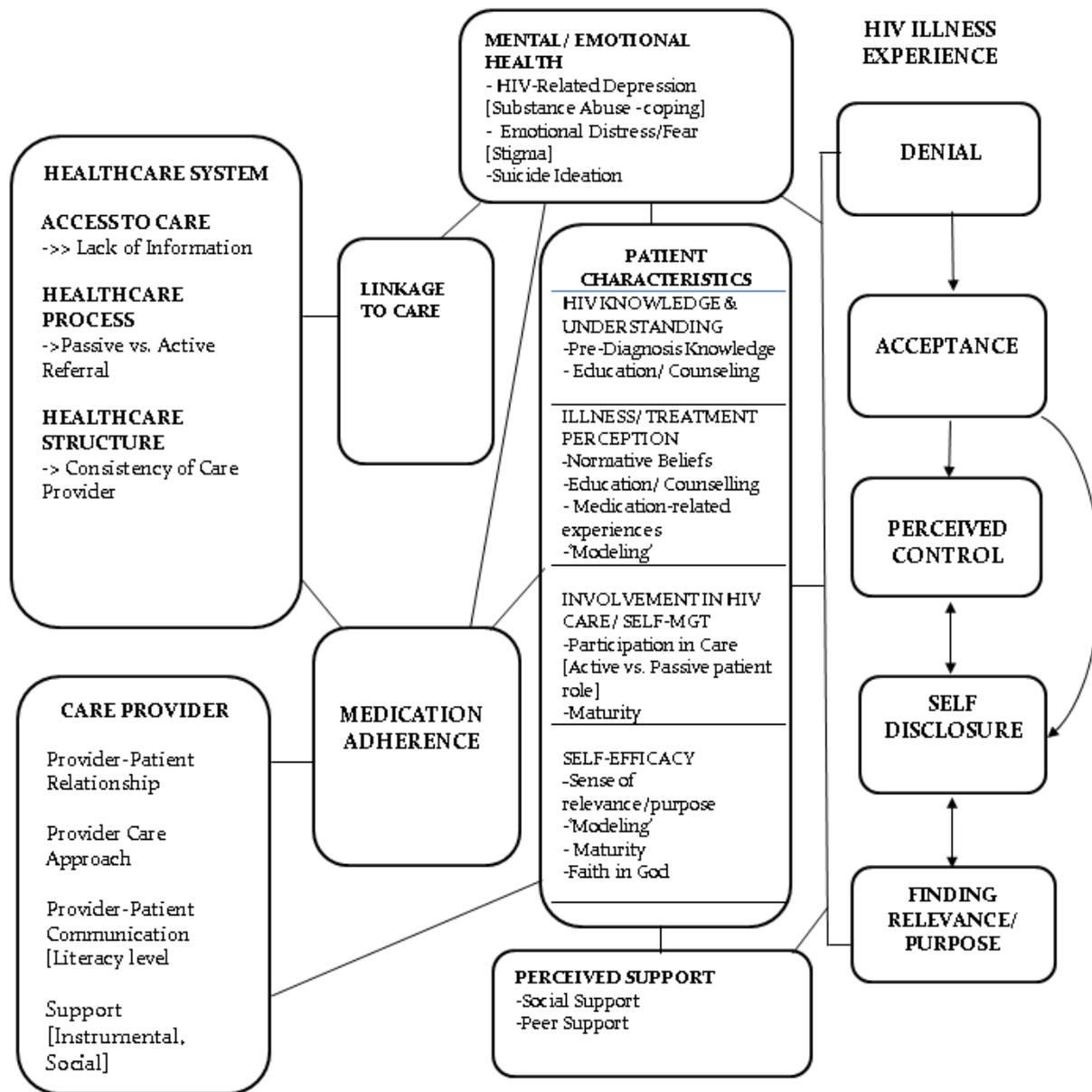


Figure 4-2. Conceptual model: Care-seeking & adherence behavior among African American women living with HIV/AIDS – patient perceptions

CHAPTER 5 DISCUSSION AND CONCLUSIONS

In this chapter, the key study findings are discussed for each study objective. Conclusions drawn are stated along with providers' recommendations for changes in practice to ensure more patient-centered care. Future research directions are also discussed.

Study Objective 1

The first study objective was to derive a comparative model of medication adherence behavior of African American women living with HIV/AIDS based on health care provider perceptions and experiences. The conceptual model was developed based on care provider perceptions and experiences as narrated in their interviews (Figure 4.1 above). The model is similar to the conceptual model developed from patients' perceptions (Figure 4.2 above) – both had the same basic components interacting to influence the treatment process in the target population – the patient, the provider and the healthcare system. In addition to these components, the model developed from provider perceptions included the socio-economic context of the target population as an underlying factor enabling many of the barriers to linkage to care and medication adherence in the target population. This component may not have been obvious in patients' narratives because it was the reality they lived in and participants may not have readily made the connections between their social and economic circumstances and the barriers/facilitators of adherence to their medications.

Other differences in the models were the mental and emotional health element as well as sub themes under the healthcare system and provider-related characteristics. These are all discussed in more detail in subsequent sections.

Study Objective 2

The second study objective was to compare patient perceptions and health care provider perceptions of factors that help to facilitate early linkage of African American women newly diagnosed with HIV to care. Care providers identified patient-related and healthcare system-related factors that they considered to influence early linkage to care in the target population. These included the following –

1. Patients' illness experience: Acceptance of HIV status versus being in denial
2. Active versus passive referral
3. Housing as a major socio-economic factor

Patients' illness experience – acceptance of HIV status: According to provider perceptions, patients who are still in a state of denial are not likely to engage in care even when linkage has been facilitated by care providers. The key factor that providers perceived to drive the care-seeking behavior of these patients is the perception of HIV disease and /or treatment. The lack of HIV knowledge and misconceptions about the disease was reportedly based on normative beliefs the patients had prior to HIV diagnosis. This mirrors the perceptions of the patients interviewed in the preliminary study regarding barriers to early linkage to care. Members of the target population interviewed reported that they did not seek care when they are initially diagnosed because they are in denial. This is also consistent with findings from other studies where denial of HIV status has been cited as a major barrier to entry into HIV care

(Konkle-Parker, Amico & Henderson, 2010; Jenness et al., 2012). The longer newly diagnosed persons stay in denial, the longer it takes for them to enter into care.

Provider: The people that aren't ready to accept their diagnosis and be in care, I feel like those are the people that really need the mental health counseling services. They really need someone to talk to, to help get them through that diagnosis and make them realize, "It's okay. You can live through this." What happens to them? I don't know. Sometimes, we get 'em a year later. Sometimes, we get 'em six months later. [Provider #10]

Patient: [**Question: So in those 6 months (following diagnosis) what were you thinking?** How were you living?] In that 6 months period of time I was just blank. I was trying to numb everything out. I wasn't trying to think about the disease at the time. I was just trying to get it out of my mind. With that I did drugs to keep it out . . . yeah, to wash it away. [Patient #03]

According to findings from a study by Fagan et al. (2012), change in patient's perceptions may be an additional step to acceptance of HIV status for patients to enter into care. Fagan et al. in their investigation focused on persons living with HIV who had never been in care. One of the reasons that some of the participants in their study gave for not seeking treatment was the belief that though they were seropositive, medical care was not necessary if one was not sick. Hence even though these patients had accepted their status, they did not see the need for care since they had not experienced any symptoms of disease yet. In this dissertation research, neither providers nor patients talked about patients' perception of the necessity of HIV treatment. This was noted and has been included for investigation in future research.

Healthcare system related – active versus passive referral: A key factor perceived as facilitating early linkage to care in this population is the initiation of an active referral process following HIV diagnosis. Care providers (specifically case managers) described an engagement process whereby patients newly diagnosed are

asked to call supportive services (to determine eligibility for financial aid with treatment, housing, etc.) right there from the care setting where they were told of their status. An appointment was then quickly scheduled – giving the potential client the option of a home visit or meeting in any other venue of mutual convenience. On certification of eligibility, clients may then enroll in care at the County Health Department. While patients interviewed in the preliminary study did not explain the process in this detail, those who entered care soon after diagnosis were generally those who were given guidance on how and where to access care, and had an appointment fixed for them to see a care provider. These were generally those who had their diagnosis done at the County Health Department. Those who had their test results shared with them in other facilities (for example, drug rehabilitation center) were simply told to seek medical care at the health department or other healthcare facilities.

The active referral described refers to ‘how’ newly diagnosed patients are enrolled into care. However, there are concerns about the timing of this referral process. Most patients from the target population are described by both providers and patients as being in a state of emotional upheaval at the time they are told of their diagnosis. Thus for some of these patients, even when they were actively referred, there was no guarantee that they would follow through as most of the information given to them at diagnosis was unlikely to be retained. There are study findings that demonstrate that following HIV diagnosis, when referrals to HIV care and support services are facilitated for the patient by someone else who is designated with this responsibility (e.g. case manager), they were more likely to follow through with entry into care in a timely manner (Gardner, Metsch, et.al., 2005; Gilman, Hidalgo, Thomas, et.al., 2012). However, more

research is needed to determine how effective the active referral process is when initiated immediately after diagnosis in this population versus when the newly diagnosed person is more accepting of their status and more receptive to information.

Provider: "I was told I need to call here. The health department told me I needed—" . . . Right. Before I really get into, "Let me get all of this information that I have to get from you on the phone," I explain the process of, "Okay, in order to get your services for free at the health department, to see the doctor, to get your medications for free, you have to come to this program. I will meet with you in person. We'll go over this paperwork. I need all of this information. Then, I will refer you and point you in the direction of the services that you need." Then, they usually have a little bit of a better grasp of it. Then, when I meet with them in person is when we really can sit down and talk about, "Okay, you've been diagnosed. Now, this is your next step. This is what you need to do. Here's what I'm gonna do to help you along the way." [Provider #10 – *explaining the referral process*]

Patient: When I got the news they immediately made the appointment for me because see at that time I was living out in ----- County at that and they made doctor's appointment for me so I could immediately be put on the meds. [Patient #08]

Housing opportunity: Another factor perceived by care providers as facilitating early linkage to care is housing. As part of care services available to PLWHIV, there is opportunity for obtaining assistance for rent payment through a program called the Housing Opportunity for Persons living with HIV/AIDS [HOPWA]. There were suggestions that persons in this population are sometimes motivated to enroll in care for the purpose of this benefit. Policies require that they be enrolled in care to be considered for this service. However, participants in the patient study sample did not mention housing opportunity as a motivation for early linkage to care.

Provider: There'll be some—or where some clients will find out about the certain programs we offer, whether it be help with housing. "Oh I can get that? Okay, now I want eligibility." They only wanna get enrolled when they find out what they can get from it. Not to help themselves, or to be in care. [Provider #08]

Research has shown that stable housing enhances positive health outcomes among persons living with HIV (Kidder et al., 2007; Kidder et al., 2007a; Parashar, 2011). In a systematic review of studies focused on examining the association between housing and medication adherence; utilization of health and social services; health status; and HIV risk behaviors among PLWHIV, there was a significant positive association between housing stability and health-related outcomes (Leaver, 2007). As was observed by care providers in this study, when PLWHIVs are homeless, their risk for adverse outcomes increases. In the literature, housing is considered an important support mechanism in HIV care for vulnerable populations (Leaver, 2007).

Study Objective 3

The third objective was to compare patient perceptions and health care provider perceptions of factors that influence medication adherence behavior of African American women living with HIV/AIDS. Patients' and providers' perceptions of factors influencing medication adherence behavior are for the most part in concordance (Table 4-10). The factors on which both patients and providers are in agreement as being associated with medication adherence are as listed in Table 4-11. However the key provider perceptions not reflected in patients narratives that may be of significance in medication adherence behavior in this population are those on the socio-economic context of the target population and concerns around mental health. Other issues centered round patient illness experience, patient characteristics, the provider-patient interaction and the healthcare system.

Socio-economic Context

Providers interviewed emphasized the significance of patients' socio-economic circumstances. While these included components commonly used to assess socio-economic status (SES), it went beyond educational level, income and employment. Other factors such as the patient's role in the family (care-giver, bread winner), substance abuse, prostitution, incarceration, and domestic violence were reported as components that should be taken into account in assessing patients' socially and economically. The socio-economic context was therefore perceived by providers as not entirely synonymous with socio-economic status which association with medication adherence has been investigated in other studies discussed in the following section.

Socio-economic status & medication adherence: From the literature, it is not quite certain that there is a significant association between socio-economic status (SES) and medication adherence in PLWHIV. A systematic review of studies, examining the impact of income and education on HIV medication adherence did not find any conclusive evidence of this association (Adler & Newman, 2002). The study did observe a positive trend between SES components – education, income and occupation – and adherence in many of the reviewed studies. Generally SES has been shown to be an underlying factor in three major determinants of health – healthcare, environmental exposure, and health behavior (Adler & Newman, 2002). Chronic stress associated with low SES is also believed to contribute to morbidity and mortality. SES components such as education and income explain some of the racial/ethnic disparities in health and therefore need to be addressed alongside trying to change individual health behavior such as medication adherence, but a lot still remains unexplained and more research is

needed to ascertain other possible factors that contribute to these disparities (Sudano & Baker, 2006; Kirby, Taliaferro & Zuvekas, 2006).

Transportation as socio-economic factor: There are several study findings demonstrating that lack of transportation is indeed a major barrier to accessing HIV care services especially for women living in rural areas (Sanquist et al., 2011; Kempf et al., 2010; Moneyham et al., 2010). The issue of transportation can be viewed from two perspectives. It can be considered a structural level problem in terms having a public transport system in place to facilitate mobility especially in the more rural areas. It may also be considered a problem at the individual level where moving from one place to another was limited on account of one not having a car. Most of the women in the target population were described by the providers as being in the lower income bracket and had no car. If they lived in an area where there was no viable public transport system, they had to rely on relatives who they may not want to know their HIV status or use assisted transportation if available and if they qualify for it.

Lack of transportation was reported as not only affecting patient's ability to make their clinic and laboratory appointments, but was also a barrier to obtaining timely refills. For the later, mail order pharmacies have reportedly come to the rescue, but this service was not always patronized, especially if the patient had not disclosed her status and therefore did not want other family members at her home to begin to ask questions when their pills arrived in the mail. However, from the literature, there are concerns that though convenient, cost saving and having potential to enhance medication adherence (where transport is a problem), patients using mail order pharmacies may be losing out

on the benefits of face-time and medication counseling with the pharmacist especially when they are newly diagnosed patients (Kibicho, Owczarzak, and Pinkerton, 2012).

Patient-related Factors

Mental health & medication adherence: Persons with chronic illnesses, and particularly those that are considered life-threatening, commonly experience some form of psychological distress, and patients with HIV/AIDS are no different in this regard. Research findings among those living with HIV suggest that women generally experience higher levels of psychological distress when compared to men (Kennedy *et al.*, 1995; Rabkin *et al.*, 1997). More severe symptoms of depression and higher levels of anxiety have been associated with HIV-related stigma (perceived and internalized), perceived lack of social support and use of fewer active coping strategies (Prachakul, Grant & Keltner, 2007; Catz *et al.*, 2010; Vyavaharkar *et al.*, 2010). These features are typically descriptive of African American women living with HIV, as corroborated by data from our study.

The prevalence of mental health issues among African American women living with HIV was not all attributable to having HIV. Care providers interviewed reported that their medical history often showed that many of these women had mental health issues like bi-polar disorder and dementia prior to their HIV diagnosis. Findings from the study and corroboration from literature suggest that some of these conditions may be as a result of domestic/partner violence, substance abuse and prostitution which have been associated with childhood physical and sexual abuse (Goodman & Fallot, 1998). Persons who have a history of abuse tend to engage in high risk behaviors (multiple sexual partners, intravenous drug use) that make them more vulnerable to HIV infection

(Goodman & Fallot, 1998). Women living with HIV who have been abused are more likely to report symptoms of depression and anxiety, and more likely to have thought of suicide at diagnosis and more likely to attempt suicide (Gielen, McDonnel, O'Campo et al., 2005). From provider perceptions in this study, there is a high incidence of childhood/ adult physical and sexual abuse among African American women. HIV diagnosis in this sub-set of African American women was said to further compound their mental illness and greatly impact their care seeking behavior and adherence to their antiretroviral medication.

Providers also reported that mental health services where available were under-utilized because of the stigma associated with mental illnesses. In the literature, this is the case particularly in the more rural areas probably because everyone knows everyone else around. In a study by Reif et al. (2006), the investigators found that PLWHIV living in rural areas were less likely to utilize mental health services. In turn, living in rural areas was significantly associated with "being African-American, heterosexual, less educated, and having minor children in the home" (Reif et al., 2006).

Acceptance of HIV status: Denial was reported as a common experience for most people following HIV diagnosis. Both providers and patients interviewed acknowledged that persons newly diagnosed with HIV are usually overwhelmed by multiple and mixed emotions including disbelief. Until PLWHIV came to terms with having the virus, they were unlikely to be in treatment. However, where linkage to care had occurred and persons diagnosed had been initiated on antiretroviral treatment, persons still in denial were likely to be non-adherent to their medication because it was a reminder that they were infected by the virus. In another study, overcoming the denial

and becoming more accepting of their HIV state was associated with gaining control in their lives and increasing self-efficacy to effectively manage HIV which includes adherence to medications (Laws et al., 2012).

Self-disclosure & availability of social Support: Several studies have associated social support with enhanced antiretroviral medication adherence (Gonzalez et al., 2004; Ammassari et al., 2006; Holstad et al., 2006). In the target population, perceived social support has also been shown to be predictive of medication adherence (Vyavaharkar, Moneyham, et al., 2011). However, to receive social support PLWHIV need to disclose their HIV status. In the target population, providers reported that those who had disclosed their HIV status especially to family members usually received social support. In the literature, perceived availability of and satisfaction with social support has been suggested as mediating the effect of depression in African American women living with HIV (Vyavaharkar, Moneyham, et al., 2011a). Depression is considered a key predictor of medication adherence in PLWHIVs (Wendorf and Mosack, 2013). As part of the protocol of care and in appreciation of the potential impact of social support on health outcomes, providers interviewed said they routinely encourage newly diagnosed (non-adherent) patients to disclose their HIV status to someone who they perceived as most likely to be accepting of the disclosure. The goal from the provider perspective was the availability of social support with the expected outcome of enhanced medication adherence and better quality of life overall. Consistent with literature, providers reported that older persons from the target population were more hesitant to disclose their HIV status than younger women (Foster and Gaskins, 2009). However, older women living

with HIV have also been found to have better coping skills compared to their younger counterparts (Miles et al., 2007)

Patient Involvement/Self-management: Considering the chronic nature of antiretroviral treatment, providers said that part of the care goal was to have patients manage their own care. They reported that patients who took up the responsibility for their care or became involved in managing their condition were usually more compliant with taking their medication. This involved being pro-active with seeking information; asking questions about their treatment and the disease itself; and monitoring their treatment outcomes (like CD4 count and viral load). From the providers' perspective, those who were more involved in their care were usually those with more education and economic stability and the majority of the target population do not fall into that category. However, they reported that the more patients perceived themselves to be in control of their condition, the more pro-active they became in managing it. Some patients from this population were described by providers as unable to engage in self-management because of their low cognitive function or poor mental health. From the providers' perspective, this sub-group of the target population was more effectively managed on ART if they had a dependable care-giver.

Providers' perceptions in this research suggest that members of the target population were generally passive in their care process. From the interviews with care providers there was a clear expectation of patients in this population to take responsibility for their care. In the literature however, there is some contrast to this expectation. A recent study by Nazione and Silk (2013) examined the intentions of providers to help patients and their self-reported bias based on race/ethnicity and

perceived patient responsibility. From their findings, providers' intention to help (including having empathy) was influenced by their perception of patient responsibility; with increased perceived patient responsibility leading to increased anger and reduced willingness to help. In that study, providers' perception of patient responsibility interacted with patient race; with particular bias to African American patients based on providers' perception of patient characteristics (Nazioe and Silk, 2013). The passive role of this population may therefore be a response based on their perception of what the provider wants from them in terms of participation in care. Passive patient role may also be associated with perceived discrimination or classism; which are reported more with African American patients compared with Whites (Hausmann et al., 2011)

Motivation: While external factors such as healthcare system and provider-related characteristics are shown to have some influence in enhancing medication adherence in PLWHIV, adherence to medication is largely perceived by PLWHIV as a function of “where” they are at in their experience of the illness (Laws et al., 2012). Both patients and providers in this study acknowledged that there is an “internal” process going on that culminates in a point where persons diagnosed with HIV have some motivation to actually take their medication(s) as prescribed and stay on treatment. Motivational factors vary for individuals, but for this population, care-giver role, the desire to see their children grow up, experience of poor health (near death experience), increase in HIV knowledge and perceived efficacy of treatment were some common perceived motivators reported by providers. Providers suggested that interventions by care providers to enhance medication adherence in this population may seek ways to help patients along the continuum of their illness experience to this point of autonomous

motivation where they are more likely to be adherent to their medication. In the literature, motivational interviewing has been projected as an effective intervention strategy in behavior change to enhance medication adherence in patients dealing with chronic conditions but especially for persons living with HIV (Holstad, Dilorio & Magowe, 2006; Konkle-Parker, 2001; Cooperman & Arnsten, 2005)

Faith in God: The African American community is known for its religious beliefs and strong faith in God especially as regards his sovereignty and power over life and death (Johnson et al., 2005). As reported by patients in the preliminary study, persons diagnosed with HIV in the target population are in a very vulnerable state that often times than not made them gravitate towards the spiritual as a coping mechanism for their illness. Anecdotally, a couple of the providers acknowledged that those who had a spiritual inclination did better in terms of health outcomes. A search of literature found some evidence to support this notion. In a study by Kremer and colleagues (2009), HIV positive patients who were on treatment and believed in or relied on their spirituality to enable them to cope reported fewer side effects, fewer symptoms and better medication adherence. This suggests that those who express faith in God could be encouraged to maintain their trust in his ability to help them stay on their course of treatment and minimize any associated adverse effects. African American women in particular have been found to be very reliant on prayers as a coping strategy (Coleman et al., 2006; Coleman et al., 2006a). Providers therefore, need to be sensitive to this element (the spiritual) in the lives of the women in this population and integrate it into their care.

Peer Support: The support available from other persons living with HIV (peer support) was perceived by both patients and providers as having some influence in

medication adherence. Providers suggested that persons in this population may be more receptive to encouragement, mentoring, counseling and/or education from someone who they perceived as not only understanding what it is like to live with HIV, but had also achieved control over the disease. In confirmation, patient participants acknowledged that encounters with other PLWHIV (especially persons with similar challenges) changed their perception of HIV and antiretroviral treatment and increased their self-efficacy to stay in care and take their prescribed medication. There is limited literature on the efficacy of peer support-based interventions on medication adherence in PLWHIV, but findings suggest that peer support is associated with higher adherence levels (Simoni et al., 2007; Marino, Simoni & Silverstein, 2007). Peer-based interventions have been considered a potentially useful strategy particularly in subgroups of patients with lifestyles (prostitution, substance abuse) that pose challenges to medication adherence (Broadhead et al., 2002; Deering et al., 2009).

Change in illness/treatment perception: In the target population, knowledge of HIV and antiretroviral drugs was reportedly very low at diagnosis. Patients' poor perceptions of the disease and the treatment were often shaped by misconceptions and normative beliefs, hence the reluctance to be initiated on antiretroviral medications and a plausible reason for non-adherence when started on treatment. There was a general consensus from both groups of study participants that as patients gained more knowledge (primarily from their care provider) their perception of HIV and the treatment changed. Studies have shown that there is a correlation between patient HIV knowledge and medication adherence (Weiss et al., 2003; Jones et al., 2013). As seen in literature, patient participants attest to HIV-related knowledge aiding the change of their

perception of HIV as a “death sentence” to that of a manageable chronic ailment (Weiss et al., 2006).

Another factor credited with helping to change patients’ perceptions was the efficacy of treatment for non-adherent persons who had experienced an HIV-related health condition which may have landed them in the emergency room or for which they felt they were going to die from and then had good treatment outcomes following a period of ART adherence. This was cited by both patients and providers as a “wake-up” for some persons in this population. Gao et al. (2000) in a study investigating the relationship between disease severity, health beliefs and adherence to antiretroviral medications found that patient who were severely ill had a perception of higher risk of HIV-related complications being associated with non-adherence when compared to patients who were as yet asymptomatic. However, the investigators also found that this risk perception did not necessarily translate to medication adherence

A distinctive factor that patient participants identified as dramatically changing their illness and treatment perception was the observation of other PLWHIV who had lived with the condition for many years and were perceived to have relatively good quality of life. This they readily attributed to taking their medications as prescribed. This ‘modeling’ not only served to change their illness and treatment perception, but also increased self-efficacy to change adherence behavior. The use of “expert patients” – persons as described above - has been advocated for in interventions to enhance medication adherence in newly diagnosed patients (Decroo, et al., 2012). Their study results suggest that apart from being a motivational factor, other PLWHIV they can help

the newly diagnosed patient learn the self-management skills necessary for successful HIV self-care.

Medication-related experience - side-effects: In this research, treatment perception was also associated with medication adherence – mostly concerns about adverse versus efficacious effects of medication and beliefs about necessity especially for patients who had not experienced any HIV-related illness prior to diagnosis. Patient beliefs about HIV medication have been associated with adherence (Horne et al., 2004; Horne et.al., 2007). Side effects were identified as a major barrier to medication adherence; with some patient participants attesting to stopping their treatment because of the experienced effects. However, when adequate counseling was given prior to treatment initiation and care providers worked with patients to ameliorate these effects, patients were more likely to stay on their prescribed regimen. Side effects have been associated with non-adherence in the general population of persons living with HIV (Ammassari, et al., 2001; Achappa, et al., 2013).

Medication-related experience - regimen: A point of subtle divergence in patients' and providers perceptions of barriers to medication adherence was the overwhelming chronic administration which patients were more concerned with as opposed to the complexity of the regimen that providers reported as a barrier. It is however arguable that the regimen is more overwhelming when there are multiple pills and/or several doses to take daily. With simpler regimen, patients were reported by providers as being more likely to adhere to their prescribed regimen. There are several studies linking the complexity of antiretroviral regimen to medication adherence (Stone et al., 2001; Trotta et al., 2002; Portsmouth et al., 2005). Providers in this study talked

about emphasizing to patients the prospect of losing a simple regimen (like the one pill a day dosing) to a more complex regimen with increased likelihood of side effects if they continued to be non-adherent to their current regimen. Reportedly, this serves to motivate some patients on a simple regimen to be adherent as they usually would not want to have to deal with multiple dosing and polypharmacy.

Healthcare System-related Factors

Consistent care provider & personal knowledge of patient: In terms of how care is structured, there were concerns about having a consistent care provider. Some of the target population access clinical care at sites where different care providers are rotated through the clinic days. Patients have no guarantee that the same care provider will be available at each follow-up clinic visit. At the academic health care setting, if patients preferred, they could see a particular member of the medical team if the person requested at the time of clinic visit was available. In this study, patients' reported that having a consistent provider enhanced provider-patient relationship whereas having different attending clinicians was associated with lower patient satisfaction with care, communication gaps in the care process, and unnecessary changes in regimen. The strategy that some of the providers reportedly adopted was to build a relationship with the patient as a team and share pertinent patient information with each other using the electronic medical records. However, patient participants in this research stressed the importance of being known personally by their care provider. Those who had a consistent care provider were more likely to establish a personal relationship with their providers. It was important to the patient that the provider knew them as a person (not just their medical history) and this is in consonance with findings in the literature (Brion,

2013). Again, while electronic medical records are helpful in sharing patient information, providers still have to select and note what non-medical information that they think is relevant to care and this would differ from provider to provider. For patients interviewed in this study, being known personally by their care provider increased their confidence in his/her recommendations for their care as they believed that their context was put into consideration in prescribing medications and making health-related recommendations for them.

Care Provider-related Factors

Provider-patient relationship: The key characteristic of the provider-patient relationship as emphasized by both patients' and providers in our study samples was care and commitment from the provider. When patients perceived that the person(s) delivering medical care really cared about them and demonstrated that they had a stake in their wellbeing, they often would respond by making the effort to take their medications knowing that their clinical values would alert the provider if they were non-adherent. Thus, a "partnership" evolved and the goal became to work together to get the viral load to the level where it was undetectable by the usual laboratory tests. This is consistent with other studies where a caring attitude and a partnership rather than a paternalistic relationship was preferred by patients (Brion, 2013; Mallinson et al., 2007).

Another characteristic of the provider-patient relationship identified was accessibility of the care provider outside clinic hours. Knowing that they could reach their care provider at any time to discuss their HIV-related concerns and have any medication-related challenges addressed immediately ensured that patients stayed on their medication as opposed to stopping the medication and waiting till the next clinic

appointment to talk to their provider. Knowing that that they could reach their provider at any time was also reported to convey a sense of being cared for and being relevant as also corroborated by another study that assessed provider-patient relationship in association with patients' adherence behavior (Brion, 2013).

Trust has long been an issue with health care in the African American population (Halbert et al., 2006; Jacobs et al., 2006; Kennedy et al., 2007). In HIV care, persons from minority populations are more likely to report experiences of discrimination in healthcare interactions and incomplete trust in their healthcare provider (Thrasher et al., 2008). To establish a viable relationship, patients in the target population often need to be assured that care providers who are more often than not non-African American, genuinely have their interest at heart. Care providers reported that building trust with this population was an intentional process aimed at getting the patients to become comfortable with interacting with them and being open to share their concerns, challenges and other information that may be useful in decision-making for their treatment. Having trust in their care provider has been cited by PLWHIVs as being a key influence in their adherence behavior (Malcolm et al., 2003; Graham et al., 2010). Knowing the patient personally is also important to patients, and this is not uncommon among patients living with HIV (Brion, 2013).

Provider care approach: Most members of the target population become infected with HIV through heterosexual contact. In the African American community, there is a prevalent notion that contracting HIV is an indication of a promiscuous lifestyle hence the associated stigma (Konkle-Parker, 2013). Providers reported that even legitimately married African American women who have been faithful to their significant

other that become infected still experience some shame and guilt. When patients perceive any hint of judgmental attitude from the provider, they are unlikely to open up about their health-related problems and non-medical challenges that could impact treatment. As a consequence, these could remain unaddressed resulting in poor adherence to medication. Providers emphasized the need to intentionally try to communicate a non-judgmental attitude to these patients through actions, words and a show of empathy. Essentially, patients who perceived a judgmental attitude from care providers reportedly were likely to be less communicative about the context of their lives – withholding information that may be pertinent to the delivery of competent care.

African American women have historically lived under the internalized stress brought on by experiences of racism, segregation and discrimination - actual and perceived (William, 1999). In addition, perceptions of HIV disease shaped by normative beliefs at the time of diagnosis have been associated with internalized stigma (Konkle-Parker, 2013). With these internalized feelings, positive response to care was reportedly enhanced if patients from this population perceived that they were being treated as individual persons versus being “just another patient”. This appreciation of them as persons (as acknowledged by both providers and patients) was all the more impactful when providers reached out to express their care, concern, or empathy with physical touch such as a hug. Physical touch has been shown to give PLWHIV a re-assurance that they are still “normal” human beings and helps their perception of the disease as a condition that does not in any way take away from the person they are (Brion, 2013).

Living with HIV is not just a medical condition; it has huge impact on the psycho-social and socio-economic aspects of one’s life. While the condition can be viewed

medically, the illness is experienced differently by the patient; affecting daily living, social interactions and economic activities. To provide care effectively, providers stressed the need to consider and address other aspects of the patients' lives as these are often sources of barriers to medication adherence in this population.

Celebrating the achievement of care goals - whether as little as showing up for their scheduled clinic visit or as much as getting viral load down to an undetectable level – is important in this patient population, considering the burden of other competing needs they have in their lives. Care providers likened this to being the patients' cheer leader. Positive re-enforcement is strategic in keeping patients motivated to meet their clinic appointments and stay on their medication.

Transportation as a structural barrier in access to care: Transportation is a significant problem for the target population and especially for those living in rural areas (Sanquist et al., 2011; Pellowski, 2013). In more urban areas, persons who do not have cars are able to get to their clinic appointments because there is an organized public transport system. However in rural areas, where there is no public system in place, it is more difficult to get to the clinic especially if the care site is not within the same county. In area 3/13, some county health departments do not have enough clientele to warrant having full time HIV care providers assigned to them. Patients then have to go to other counties for care. Providers noted that making arrangements for assisted transportation can be very overwhelming for persons in this population because of other competing needs and the multiple roles they play in their families.

Study Objective 4

Objective 4 was to explore differences between health care provider perceptions of medication adherence needs of African American women living with HIV/AIDS and current HIV care practices.

Providers' recommendations: To provide more patient-centered care to this population, health care providers made suggestions on how the structure and process of care could be modified. The key suggestions include –

1. Focusing on patients' immediate emotional and psycho-social needs at time of diagnosis;
2. Minimizing the red tape associated with HIV care (especially the paper work); and
3. Reviewing and revising medication related policies that do not promote medication adherence for patients.

Focus on immediate emotional and psycho-social needs: At the time of diagnosis, most people are overwhelmed by the news of their status. Patients commonly experience a range of emotions – shock, fear, anger, depression, disbelief. For most PLWHIV, their immediate concerns are non-medical as they are confronted with a condition that will affect all aspects of their lives going forward. Their emotional state is described as often unstable and it usually takes time for them to process what they just heard and come to terms with it. A lot of information is given to the newly diagnosed which they may not be able to assimilate at that point. HRSA guidelines recommend that care providers assess patients' emotional state and be cognizant of its impact on their ability to retain and act on information given to them. By inference, trying to get newly diagnosed persons to enroll in care immediately may often be ineffective.

Providers recommend that efforts should be channeled towards addressing patients' immediate concerns; the goal being to get them to come back. Talks about treatment can be initiated in follow-up visits.

There are concerns from the provider perspective about patients who are not immediately enrolled in care before they leave the facility following disclosure of their status, getting lost to follow up. This is the point where peer educators/navigators are thought to be most useful in connecting with and helping to address concerns that the newly diagnosed patients may have. Providers suggest that newly diagnosed patients may also be more open to home visits by peers or just further interaction with others living with HIV (peers). These peers could help to educate and help them come to terms with the condition and begin to build self-efficacy to manage it like any other chronic condition.

Minimize the red tape associated with HIV care (paper work): Providers acknowledged that while some of the policies associated with HIV care are laudable in theory, when implemented may not work to produce the ultimate care goal which is the health outcome of persons in this population. The paperwork that is required for assurance of eligibility to access assistance for care and related services is reportedly aimed at minimizing expenditure as it ensures that persons who receive these services are in need of them. However, the effort needed to keep up with the process of re-certification every six months may be more than some members of the target population are willing and/or able to deal with. These women have so much to take on in their lives that the additional paperwork may just constitute more of a challenge than facilitating the care process for them. Frequent breaks in care (and consequently medication refills)

due to defaults in eligibility contribute to non-adherence in this population and possibly development of drug resistance.

Review and revise policies that do not promote medication adherence:

Providers acknowledge that policies are necessary in any system and the health care system is no different. However, they argued that policies need to be flexible to accommodate differences in patient populations. They recommend that when patients default in meeting up with requirements for continuous enrolment in aid programs like ADAP, rather than cut off their medication supply, efforts should be made to work with patients to identify and address their challenges. Also for loss of medication or out of stock drugs, efforts should be made to give patients sufficient pills to cover the period before their next refill or the time when out of stock drug will be available respectively. Pharmacies that have clients living with HIV are urged to monitor their refills to ensure that all the drugs on the regimen are readily available.

Other recommendations made by the care providers interviewed included the use of patient advisory groups as a resource to care providers on patient perceived needs and assessment of adequacy of care being provided; peer educators/navigators; and the teach back technique in provider-patient communication.

Patient Advisory Groups [PAGs]: Using patient advisory groups (PAGs) is recommended by the Health Resources and Services Administration as a valuable tool to providers for the delivery of patient-centered care in patient populations living with HIV (HRSA). The Health Resources and Services Administration (HRSA), is an agency of the U.S. Department of Health and Human Services, which primary function is the

improvement of access to health care services the uninsured, isolated or medically vulnerable populations (HRSA). The PAG is a patient panel that makes suggestions to providers and advises them from a patient perspective on ways to improve patient care and satisfaction. It involves –“identifying clinic problems, recommending changes in the care delivery system, and discussing new treatment approaches” [HRSA]. Very limited research has been done to determine the impact of PAGs in HIV care outcomes, but there are studies demonstrating the potential for patients as educators to health care providers (Towle et al., 2010; Towle & Godolphin, 2013; Doucet et al., 2013).

A medical treatment model that uses the same principles as the patient advisory group described above is the ‘Group outpatient visit model’ whereby groups of patients meet with their care provider for their usual clinic visit as opposed to meeting with the care physician one-on-one. Patients in this group setting would usually receive education on their disease condition but also have opportunity to communicate their concerns to the care provider as well as ask questions. This model of care has been shown to be effective in improving health outcomes and enhancing patient satisfaction with care in chronic disease management (Sadur et al., 1999; Wagner et al., 2001; Scott et al., 2004). By inference, there may be potential benefit in the use of patient advisory groups to improve medication adherence in the target population.

Peer educators/ navigators: There is a lot of ‘push’ for the utilization of peer educators and peer navigators in HIV care as an effective strategy in helping patients build self-management skills, overcome care-related barriers and increase in HIV knowledge; while also facilitating entry into and retention in care, and medication adherence (HRSA, 2009; Ryan White, 2010; IAPAC, 2013). Research findings

demonstrate that including other persons living with HIV who are successfully managing their condition and are knowledgeable about the disease and treatment in the care team is beneficial in facilitating entry and retention in care, and also medication adherence particularly among vulnerable populations like the target group (HRSA, 2013; PEERC; Turner, & Shepherd, 1999; Population Council).

Read-back/Teach back in patient communication: There are concerns that based on literacy level and language barrier (some care givers are “aliens” and speak English with a distinct foreign accent) some patients may not easily understand the information being passed on to them. More often than not, when patients are asked if they ‘get’ all that has been conveyed to them, they say they do when actually they may not. The read-back or “teach back” strategy is a highly endorsed tool in patient communication and has been shown to improve patient understanding and consequently health outcomes (The Joint Commission, 2007; Indian Health Service; NCEHC, 2006; Kripalani & Weiss, 2006).

Conclusions

Care seeking behavior and medication adherence among African American women living with HIV/AIDS are products of the complex interplay of personal, interpersonal, and structural level factors influenced by patients’ socio-economic context.

Key finding #1 – Provider insight is critical to understanding barriers to care for the target population: Patients are more acutely aware of the personal and interpersonal factors that influence their HIV-care related and medication taking behaviors. Compared to patients, healthcare providers are in addition, also

knowledgeable about the broader context of the barriers to early linkage to care and medication adherence in this population. These barriers are more structural and socio-economic (for example housing, transportation, availability and accessibility of mental health services, and policies about dispensing of medications). Patients from the target population that were interviewed did not mention these barriers suggesting that they may not be aware of the impact these factors have on their ability to access care and stay on course with their regimen or simply accept these as how the system is structured. Providers have a more comprehensive overview of these barriers and how they influence patient behavior and care outcomes. They are therefore strategically positioned to strongly advocate for policies that provide more patient-centered care and eliminate some of the structural barriers to care and medication adherence in this population.

Key finding #2 – Patient’s illness experience: While structural level problems (such as the fragmentation of the health care system, restrictive policies and the unavailability of transportation) are significant barriers, they may only make it more difficult for patients in the target population to access and/or stay in care if they are actually willing to engage in HIV treatment. The patient’s ‘journey’ through her illness experience may be the key limiting factor to change in health related behavior. Interactions with other PLWHIV and health care providers can positively impact this experience. Understanding the illness trajectory of the patient can help health care providers better evaluate and monitor patients. Providers can also utilize appropriate tools and strategies (such as peer education/ navigation, HIV education) to expedite the

internal illness process and get them to the point where they are not only willing or motivated, but have the self-efficacy to effectively engage in self-care.

Key finding #3 – Impact of patient’s socio-economic context: The narratives of the providers as well as findings from the literature suggest that the relationship between race/ethnicity and medication adherence may be confounded by socio-economic status which includes variables such as income level, housing, education, employment status and place of residence (rural versus urban). However, after controlling for these variables, racial/ethnic disparities in HIV care-seeking and health-related behaviors still persist. These variables differentiate sub-sets of patients within this population who may have unique problems associated with entry into and retention in care, and medication adherence, but do not fully explain the disparities. Findings from this study suggest that there are characteristics of the socio-economic context of the target population that include but also go beyond the SES. There are contextual factors that are unique to sub-groups within this population. These include the care-giver role; carrying the financial burden of the home; history of sexual abuse; prevalence of domestic violence; and the instability with employment, relationships and housing. Providers should actively seek to understand each patient’s context, and take it into account in their care delivery. Interventions to facilitate linkage to care and/or enhance medication adherence therefore need to be tailored to individual patients or designed to target specific sub-groups within this patient population.

Key finding #4 – Potential for significant impact using peer educators/ navigators: Patient perspectives strongly suggest that interaction with other PLWHIV who are perceived as having a good quality of life (QoL) significantly affects perception

of HIV disease and ART. Newly diagnosed patients from the target population, who perceive this health outcome (QoL) to be attributable to effective treatment with ART, are more accepting of HIV treatment more likely enter into care early. Interaction with peers (especially those with similar demographics socio-economic context) also helps to increase self-efficacy for medication adherence in this population. Formal training and inclusion of peers in HIV care as educators and/or navigators should therefore be considered as a potentially effective strategy in improving early linkage and medication adherence in this population

Key finding #5 – The patient as the ‘expert’ in their care delivery: Provider perspectives on potential strategies to enhance competency of care delivery to this population support the recommendations by HRSA to utilize PAGs as a tool in HIV care. Members of the target population are characteristically described as passive in their patient role and may not readily give feedback to their care providers on their satisfaction with care while in the care setting. However, they may be more forthcoming in a non-clinical setting where they are invited as advisors to share their experiences from interaction with the healthcare system and care providers. Such a forum would give providers an opportunity to gain insight into any challenges this patient population faces in the process of accessing and receiving care. The recruitment of patients as ‘experts’ in their care is expected to guide policy-making that is more patient-centered and provide constructive feedback that would enable healthcare providers deliver more competent care to the target population.

This study gives a broad overview of barriers and facilitators associated with linkage to care and medication adherence in the target population. The factors identified

provide useful information for the design of interventions. However, more research is recommended to determine the specific mechanisms by which these factors exert influence on health-related behavior in this population.

Study Limitations

Volunteer bias: The study sample in the preliminary study was skewed in that persons who volunteered to participate in the study were mostly middle aged to elderly women who had similar characteristics. They were all enrolled in care and self-reported high levels of adherence. Most of them were involved in support groups and some had publicly disclosed their HIV status and openly engaged in HIV advocacy activities in their communities. Their perceptions may differ markedly from those who are not currently engaged in care, have been lost to follow-up or are non-adherent to their antiretroviral medications. Efforts were made to recruit persons out of care, but did not meet with any success as confidentiality policies precluded approaching persons in the target population unless they initiate contact with the investigator. Interviews with patient participants therefore sought to explore their earlier experiences with HIV and health-related behavior prior to becoming adherent. While one may argue that recall bias is a potential issue, there is every reason to believe that patients' recall is accurate given the pivotal and life changing nature of an HIV diagnosis.

Convenience sampling & selection bias: While purposeful in the sampling approach (careful to include diverse types of providers), there was an obvious *selection bias*. Care providers approached to participate in the study were those whose contact information was available, and those who consented were essentially agreeing to invest their time despite their busy schedule. Participants therefore may be those overly

concerned about the target population and their views may not accurately represent the general perceptions of all care providers in the target area (3/13).

Sample size & generalizability: The study samples (for both patients and care providers) were relatively small compared to the sizes of the actual populations of the target group and care providers, respectively. This does not limit the applicability of the findings in designing interventions for African American women living with HIV/AIDS within the target region (area 3/13) since interviews for both patient participants and care providers were conducted until the point of saturation was reached. However, application of the findings to women in the target group residing in other areas is dependent on the similarities of their context to the population studied. Hence some validation may be required in other populations. It should be noted that the study was not inferential, but rather exploratory. While the methodological approach is considered appropriate and sample size adequate, further research is needed to validate these findings.

Personal bias: By the very nature of the study (qualitative), there is potential for personal bias. Time and resources were limited hence data coding and analysis was done by a single researcher. Inter-rater reliability assessment of assigned codes and categorizations to make the findings less subjective was not feasible. However, member check was done whereby some of the participants ($n = 8$) were presented with the findings for confirmation that they were accurate representations of their perceptions as opposed to researcher's interpretations. In addition, the researcher wrote a reflexivity note where her assumptions were outlined to help distinguish between her perceptions and those of the participants.

Potential response bias: The investigator who conducted the interview is a black female, though not African American. Perception of the interviewer as being closely associated with the racial background of the target population may have influenced participants' responses. Most of the participants for the study were white, Caucasian. Again, most of the care providers interviewed have a diverse patient population. There were responses to interview questions that tended to apply to the general population of patients living with HIV and not necessarily to the target population. Efforts were made during the interviews to intermittently remind participants that questions were specific to the target population.

Next Steps - Designing Targeted Interventions

Ultimately, the purpose of this research is to facilitate the design of targeted interventions that can facilitate early linkage to HIV care and enhance medication adherence in among African American women living with HIV. This portion of the research has identified numerous issue associated with linkage and medication adherence as perceived by both patients and care providers. These provide useful information to stakeholders interested in implementing programs aimed at addressing HIV-related morbidity and mortality in the target population. An overview of the factors identified is given in an integrated model (Figure 5-1).

Integration of Conceptual Models

The various factors identified by patients in the target group and those drawn from the perceptions of healthcare providers have been integrated into one conceptual model. The result is a comprehensive model describing the potential interactions between factors at the individual, inter-personal and structural levels that affect care-

seeking behavior and medication adherence in the target group. While some of the factors identified are not necessarily the same from both patients' and providers' perspectives, a search of literature confirms that all the factors mentioned directly or indirectly affect how members of the target group enter into care and take their antiretroviral medication (preliminary study in chapter one and the discussion section in the following chapter). The integrated model provides a comprehensive overview of factors associated with medication adherence in the target population and provides more holistic picture useful in selecting an area(s) of focus and designing effective interventions (Table 5-1).

Selecting an Intervention Focus: Priority Matrix

From the research, several factors have been identified as influencing or affecting medication adherence behavior in the target population. A number of intervention strategies are also suggested based on recommendations from both patients' interviewed and the health care providers. However, resources are always limited and in implementing an intervention, the goal is usually to select an area(s) of focus that achieves the most impact for the resources invested. To determine the area(s) to focus on for intervention in the target, a priority matrix was constructed (Figure 5-2). The matrix differentiates problem areas based on two criteria – [1.] the importance of its influence on the targeted behavior and [2.] the degree to which it is amenable to change. The factors that are more important and easier to change are those recommended for focus in designing a cost-effective intervention(s) in the target population. Moving forward, two key areas will be focused on for further research and intervention – peer support and patient advisory groups.

Impact of Peer Education/Navigation on Linkage to care and Medication Adherence

Findings from this study strongly suggest that peer navigation and peer support may be very significant in facilitating early linkage to HIV care and enhancing medication adherence in the target population. Peer support was perceived by patients interviewed to have significant impact on linkage to care and medication adherence. While providers agreed that there may be some benefit to integrating peer educators and/or navigators into the HIV care team, there is no documented evidence yet of the impact in the target population. Future research efforts will therefore focus on determining the impact of peer support (peer education and peer navigation) on linkage to care and medication adherence among African American women living with HIV/AIDS.

Implementing a Patient Advisory Group

One of the recommendations from care providers interviewed in this dissertation research was the establishment of patient advisory groups from the target population. Another research being considered is the implementation and evaluation of the impact of an HIV patient advisory group intervention on health care providers' attitudes and knowledge of patient needs.

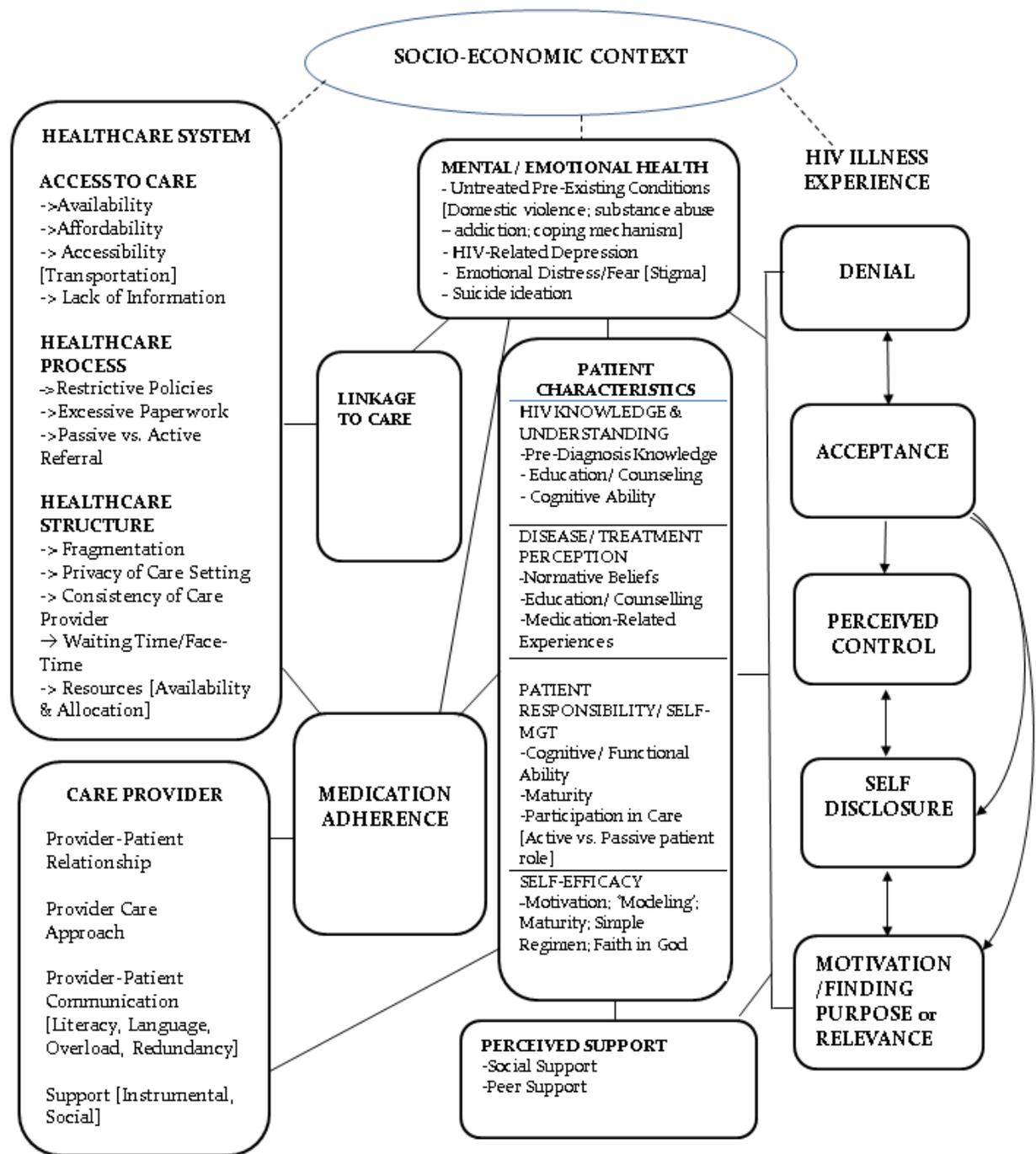


Figure 5-1. Integrated model: Care-provider and patient perceptions of care-seeking & adherence behavior among African American women living with HIV/AIDS

Prioritization Matrix

	MORE IMPORTANT	LESS IMPORTANT
MORE CHANGE- ABLE	<ul style="list-style-type: none"> ▪ High priority for program focus: 1. Referral protocol 2. HIV/treatment perception 3. Provider care approach [PAGs] 4. Peer support 5. Restrictive policies 	<ul style="list-style-type: none"> ▪ Low priority:
LESS CHANGE- ABLE	<ul style="list-style-type: none"> ▪ Priority; evaluation crucial: 1. Transportation 2. Substance abuse 3. Social support 4. Distrust of healthcare system 5. Mental health/Depression 	<ul style="list-style-type: none"> ▪ No program 1. SES – [low income, unemployment] 2. Low literacy/ education

Figure 5-2. Priority matrix - Selecting target areas for intervention

APPENDIX A
PATIENT INTERVIEW GUIDE

Demographic Data (pre-interview)

1. Ethnicity Native born African American African
 Caribbean
2. Country of birth United States of America Other country

3. Age: < 20yrs 20 – 24yrs 25-29yrs
 30 – 34yrs 35- 39yrs 40yrs and above
4. Marital Status: Single Married Separated
 Divorced Widowed
5. How many children do you have? -

6. In which year were you diagnosed with HIV?

7. What is the highest level of education you have had?
 No education Elementary/Middle school (State Grade
level) _____
 High school College Graduate school
8. Are you currently employed?
 Yes , if so, full-time or part-time?

 No

Interview Guide

Questions/*Prompts

1. Do you remember when you were first diagnosed with HIV? Can you tell me about it?

- Prompts – i. The circumstance
 ii. Where were you?
 iii. Who told you?
 iv. How were you told?

2. What was your initial reaction on learning that you were positive?

- Prompts – i. How did you feel? About the disease, yourself, your life, etc.
ii. What did you do?
iii. Did you have any concern(s) at that time?
iv. Would anything have made a difference?

3. When did you start taking HIV drugs? Can you tell me how you started?

- Prompts – i. How long was it from the time you knew you were positive?
ii. What was the experience like?
iii. Do you think you were ready to start taking the drugs? Why?
iv. How did you feel about taking the drugs?
v. How were you taking the drugs?
vi. Did you have any challenges?

4. What has been your experience with the drugs since then?

- Prompts – i. Are you still taking the drugs?
ii. How are you taking the drugs now? Why?
iii. How do you feel about taking the drugs now?
iv. Have there been any changes in how you take your drugs? If so, what? When? How? Why?

5. Given your experiences, what do you think can be done to help other African American women who are living with HIV become more adherent to their medication?

*Prompts – To be used ONLY when necessary. Otherwise, participants will be allowed to just talk about their experiences as related to medication use.

APPENDIX B
PROVIDER INTERVIEW GUIDE

Protocol Title: Health care provider perceptions about medication adherence among African American women living with HIV/AIDS

1. Please tell me about your general experience with African American women living with HIV/AIDS

Prompts

- How would you describe this population?
- How is this population similar and/or different from other populations living with HIV/AIDS?

2. Drawing from your experience, can you describe what your first encounter with an African American woman newly diagnosed with HIV would typically be like?

Prompts

- Your assumptions (if any)
- Your approach
- Care process

3. Can you tell me about any specific concerns that you may have about this population?

Prompts

- With regards to linkage to care
- With regards to medication adherence

4. How would you compare African American women living with HIV with women from other racial/ethnic backgrounds also living with HIV/AIDS with regards to what facilitates –

- Linkage to care
- Medication adherence

5. What do you think is the care provider's role in enhancing medication adherence in this population? In what way(s) can other healthcare providers enhance medication adherence in this population?
6. Can you tell me what specific things you as a health care provider are doing to enhance medication adherence in this population?
7. In your assessment, how efficient is the health care system in
 - a. getting persons in this population into care
 - b. following up clients to ensure retention in care
8. In your assessment, how helpful are
 - (i.) health care providers such as yourself and
 - (ii.) the healthcare system in general in -
 - a. Facilitating linkage to care for members of this population
 - b. Enhancing medication adherence among your clients in this population?
9. What do you think will be most helpful in improving medication adherence in this population?

APPENDIX C
PROVIDER DEMOGRAPHIC INFORMATION FORM

Protocol Title: Health care provider perceptions and beliefs about medication adherence among African American women living with HIV/AIDS

We would like to ask you a few questions about your demographic characteristics. This is to facilitate the interpretation of the data collected from this interview.

1. What is your primary professional discipline?

- Nurse Practitioner
- Pharmacist
- Physician
- Health Educator
- Mental/Behavioral Health Professional
- Other Public Health Professional
- Social Worker
- Substance Abuse Professional
- Community Health Worker
- Other (*please specify*): _____

1a. How long have you been in this professional discipline? (*Please state no. of years*) _____

2. What is your primary functional role in HIV care?

- Clinician
- Nurse
- Case Manager
- Pharmacist

2a. How long have you been functioning in this role? (*Please state no. of years*)

3. What is your primary employment setting? Name of agency

3a. Type of agency

- State/Local Health Dept.
- Academic Health Center
- Private Practice
- Other (*please specify*) _____

3b. Location

- Rural
- Suburban
- Urban

4. Gender

- Male
- Female

5. What is your racial/ethnic group?

- Caucasian/White
- African American/Black
- American Indian/Alaska Native
- Asian American
- Latino/Hispanic
- Native Hawaiian/ Other Pacific Islander
- Other (please specify) _____

6. Are you Hispanic?

- Yes
- No

7. What is your age category?

- < 30 years
- 30 – 39 years
- 40 – 49 years
- 50 – 59 years
- 60 – 69 years
- 70 years and above

8. How long have you been working with persons living with HIV/AIDS?

(Please state no. of years/ months) _____

9. On the average, how many patients/clients living with HIV do you see in a month? _____

APPENDIX D
PROFILE OF CARE PROVIDER PARTICIPANTS

Participant #1

<i>Primary profession/ discipline</i>	Registered Nurse (RN) – 33years
<i>Primary role in HIV care</i>	Nurse/ Case manager – 14years
<i>Employment setting</i>	Non-profit organization
<i>Care site(s)</i>	Rural, suburban, urban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	60 -69 years
<i>Years working with PLWHIV</i>	40years
<i>Average no. of clients /month</i>	50 – 60

Participant #2

<i>Primary profession/ discipline</i>	Physician (primary care)– 22years
<i>Primary role in HIV care</i>	Clinician – 22years
<i>Employment setting</i>	State/County Health Department (16 years)
<i>Care site(s)</i>	Rural
<i>Gender</i>	Male
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	50 – 59 years
<i>Years working with PLWHIV</i>	22 years
<i>Average no. of clients /month</i>	10 – 15

Participant #3

<i>Primary profession/ discipline</i>	Physician (infectious disease specialist) – 19 years
<i>Primary role in HIV care</i>	Clinician – 16 years
<i>Employment setting</i>	Academic; State/County Health Dept., Non-profit Org.
<i>Care site(s)</i>	Rural
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	40-49 years
<i>Years working with PLWHIV</i>	16 years
<i>Average no. of clients /month</i>	75 – 100

Participant #4

<i>Primary profession/ discipline</i>	Social worker
<i>Primary role in HIV care</i>	Case manager
<i>Employment setting</i>	Non-profit organization
<i>Care site(s)</i>	Rural, suburban, urban
<i>Gender</i>	Male
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	60 – 69years
<i>Years working with PLWHIV</i>	5 years
<i>Average no. of clients /month</i>	Variable: 0 – 25

Appendix D continued

Participant #5	
<i>Primary profession/ discipline</i>	Social Worker – 8 years
<i>Primary role in HIV care</i>	Case manager – 3 years
<i>Employment setting</i>	Non-profit organization
<i>Care site(s)</i>	Rural, suburban, urban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Latino/Hispanic
<i>Age category</i>	30 -39 years
<i>Years working with PLWHIV</i>	3 years
<i>Average no. of clients /month</i>	About 30

Participant #6	
<i>Primary profession/ discipline</i>	Social Worker – 15 years
<i>Primary role in HIV care</i>	Case manager – 12 years
<i>Employment setting</i>	Non-profit organization
<i>Care site(s)</i>	Rural, suburban, urban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	60 -69 years
<i>Years working with PLWHIV</i>	11 years
<i>Average no. of clients /month</i>	30 – 40

Participant #7	
<i>Primary profession/ discipline</i>	Community Health Worker – 20 years
<i>Primary role in HIV care</i>	Case Manager – 12 years
<i>Employment setting</i>	Non-profit organization
<i>Care site(s)</i>	Rural, suburban, urban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	60 -69 years
<i>Years working with PLWHIV</i>	12 years
<i>Average no. of clients/month</i>	10

Participant #8	
<i>Primary profession/ discipline</i>	Social Worker – 10 years
<i>Primary role in HIV care</i>	Case manager – 5 years
<i>Employment setting</i>	Non-profit organization
<i>Care site(s)</i>	Rural, suburban, urban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	< 30 years
<i>Years working with PLWHIV</i>	5 years
<i>Average no. of clients/month</i>	About 100

Appendix D Continued

Participant #9

<i>Primary profession/ discipline</i>	Physician (<i>primary care</i>)- 20
<i>Primary role in HIV care</i>	Clinician – 17
<i>Employment setting</i>	State/County health Department; Private practice
<i>Care site(s)</i>	Sub-urban
<i>Gender</i>	Male
<i>Race/ethnicity</i>	Latino/Hispanic
<i>Age category</i>	50 -59 years
<i>Years working with PLWHIV</i>	17
<i>Average no. of clients/month</i>	> 100

Participant #10

<i>Primary profession/ discipline</i>	Social Worker – 7 years
<i>Primary role in HIV care</i>	Case manager – 7 years
<i>Employment setting</i>	Non-profit organization
<i>Care site(s)</i>	Rural, suburban, urban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	30 -39 years
<i>Years working with PLWHIV</i>	10 years
<i>Average no. of clients /month</i>	8 - 10

Participant #11

<i>Primary profession/ discipline</i>	Pharmacist – 19
<i>Primary role in HIV care</i>	Pharmacist – 15
<i>Employment setting</i>	Specialty pharmacy
<i>Care site(s)</i>	Suburban
<i>Gender</i>	Male
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	50 -59 years
<i>Years working with PLWHIV</i>	19 years
<i>Average no. of clients /month</i>	7

Participant #12

<i>Primary profession/ discipline</i>	Physician (Infectious disease specialist) – 30 years
<i>Primary role in HIV care</i>	Clinician – 30 years
<i>Employment setting</i>	Academic Health Center
<i>Care site(s)</i>	Suburban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	60-69 years
<i>Years working with PLWHIV</i>	32 years
<i>Average no. of clients (PLWHIV) seen per month</i>	20

Appendix D Continued

Participant #13	
<i>Primary profession/ discipline</i>	Nurse – 40 years
<i>Primary role in HIV care</i>	Case manager – 16 years
<i>Employment setting</i>	Academic Health Center; State/County Health
<i>Care site(s)</i>	Department
<i>Gender</i>	Rural, suburban
<i>Race/ethnicity</i>	Female
<i>Age category</i>	Caucasian, non-Hispanic
<i>Years working with PLWHIV</i>	60 -69 years
<i>Average no. of clients /month</i>	28
	50 -60

Participant #14	
<i>Primary profession/ discipline</i>	Physician– 3 years
<i>Primary role in HIV care</i>	Clinician - 1.5 years
<i>Employment setting</i>	Academic Health Center (Resident)
<i>Care site(s)</i>	Suburban
<i>Gender</i>	Male
<i>Race/ethnicity</i>	Asian, non-Hispanic
<i>Age category</i>	30 – 39 years
<i>Years working with PLWHIV</i>	3.5 years
<i>Average no. of clients /month</i>	10 -12

Participant #15	
<i>Primary profession/ discipline</i>	Physician – 7 years
<i>Primary role in HIV care</i>	Clinician - 3 years
<i>Employment setting</i>	Academic Health Center (Resident)
<i>Care site(s)</i>	Suburban
<i>Gender</i>	Male
<i>Race/ethnicity</i>	Asian, non-Hispanic
<i>Age category</i>	30 – 39 years
<i>Years working with PLWHIV</i>	10 years
<i>Average no. of clients /month</i>	8 – 10

Participant #16	
<i>Primary profession/ discipline</i>	Nurse Practitioner – 45 years; Associate Professor
<i>Primary role in HIV care</i>	Clinician
<i>Employment setting</i>	Academic; State/County Health Department
<i>Care site(s)</i>	Rural, suburban, urban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	60 -69 years
<i>Years working with PLWHIV</i>	19
<i>Average no. of clients /month</i>	30 -40

Appendix D Continued

Participant #17

<i>Primary profession/ discipline</i>	Physician (Pediatrician)– 30 years
<i>Primary role in HIV care</i>	Clinician – 30 years
<i>Employment setting</i>	Academic Health Center; outreach clinics
<i>Care site(s)</i>	Rural, suburban, urban
<i>Gender</i>	Male
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	60 – 69 years
<i>Years working with PLWHIV</i>	30 years
<i>Average no. of clients /month</i>	5 -10

Participant #18

<i>Primary profession/ discipline</i>	Medical assistant
<i>Primary role in HIV care</i>	Nurse
<i>Employment setting</i>	Private clinic
<i>Care site(s)</i>	Suburban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	30-39 years
<i>Years working with PLWHIV</i>	4 years
<i>Average no. of clients /month</i>	50

Participant #19

<i>Primary profession/ discipline</i>	Physician (Infectious disease specialist) – 12 years
<i>Primary role in HIV care</i>	Clinician – 7 years
<i>Employment setting</i>	Academic Health Center
<i>Care site(s)</i>	Suburban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Asian American, non-Hispanic
<i>Age category</i>	30-39 years
<i>Years working with PLWHIV</i>	10 years
<i>Average no. of clients /month</i>	20-25

Participant #20

<i>Primary profession/ discipline</i>	Pharmacist – 13
<i>Primary role in HIV care</i>	Pharmacist – 5
<i>Employment setting</i>	Retail pharmacy
<i>Care site(s)</i>	Suburban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	30 -39 years
<i>Years working with PLWHIV</i>	13 years
<i>Average no. of clients (PLWHIV) seen per month</i>	15-20

Appendix D Continued

Participant #21

<i>Primary profession/ discipline</i>	Pharmacist – 4
<i>Primary role in HIV care</i>	Clinical Pharmacist – 2
<i>Employment setting</i>	Academic Health Center; State/County Health Department
<i>Care site(s)</i>	Suburban
<i>Gender</i>	Female
<i>Race/ethnicity</i>	Caucasian, non-Hispanic
<i>Age category</i>	30 -39 years
<i>Years working with PLWHIV</i>	5 years
<i>Average no. of clients (PLWHIV) seen per month</i>	>100

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BIOGRAPHICAL SKETCH

Olihe Okoro earned her Bachelor of Pharmacy degree (BPharm) from the University of Nigeria in 1998. She also received her Master of Pharmacy degree in Clinical Pharmacy/Pharmacology from the same University in 2004. Prior to her admission into the PhD program, she worked as a pharmacist in diverse practice settings including retail pharmacy, pharmaceutical industry and hospital. She also worked as a volunteer pharmacist in a PEPFAR-funded HIV clinic located in a rural setting in Easter Nigeria where she developed an interest in patient outcomes research.

While pursuing her PhD in the University of Florida, Olihe worked as a teaching assistant in the Department of Pharmaceutical Outcomes and Policy, College of Pharmacy. In this role she helped to prepare course curriculum, facilitated student group discussions, graded students' assignments and exams, and taught select topics. She also worked as a research assistant on a project where she developed and taught modules to train over 200 community health workers. Alongside her PhD studies, she was enrolled in a non-traditional dual degree program and earned a Master of Public Health (MPH) in Social and Behavioral Sciences (2013).

Olihe Okoro has been a recipient of numerous honors and awards including the Faculty for the Future Scholarship for two consecutive years; Walgreen's Cultural Competency and Diversity Award and the Marilyn Little Scholarship for international students.

Olihe has carried out research focusing on cultural competency in Pharmacy Education and health disparities in HIV/AIDS. Her research has been accepted for

presentation at national and international conferences including the Annual Meetings of the Association of American Colleges of Pharmacy (AACCP) and the XIX International AIDS Conference, 2012. In addition, Olihe has published her work in the *American Journal of Pharmacy Education*.

Olihe Okoro's dissertation *Patient and Health Care Provider Perceptions on Linkage to Care and Medication Adherence among African American Women living with HIV/AIDS – A Comparative Qualitative Analysis* was supervised by Dr. Folakemi Odedina. Following her graduation, Olihe plans to continue building a career in the academia and conducting patient outcomes research.