

Examining Adherence in  
African American Women Living with HIV

by

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## **DEDICATION**

My dissertation is dedicated to my grandmother, Estelle Krahn, (aka Gma) and my mother, Carol Prosser. I know I would not be where I am today without the unwavering love and support I have received from these two women. Gma, I am sorry you aren't here to see this day. "I love you loooooooooooooooooong time."

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## **CHAPTER 1**

### **INTRODUCTION**

Since the debut of HIV in the early 1980s, several advances have been made in the care and treatment of HIV. Indisputably, the most significant was the advent of antiretroviral therapy. Antiretroviral therapy (ARV) has significantly decreased morbidity and mortality associated with HIV. As a result, persons are living longer. However, the number of persons living with HIV continues to rise in ethnically disproportionate rates. For example, African Americans represent only 12% of the U.S. population but accounted for 46% of persons living with HIV infection in 2006 and half (49%) of new AIDS diagnoses in 2007(Kaiser Family Foundation, 2009). Between 2003 and 2007, the number of African Americans living with AIDS increased by 24%, while the number of whites living with AIDS increased by 18%. In 2006, African American females accounted for approximately 12% of the United States female population but 61% of new HIV infections in women. African American women accounted for 66% of new AIDS cases in 2007 (Kaiser Family Foundation, 2009). The incidence of HIV infection rate among African American women is 15 times greater than their white counterparts. HIV was the leading cause of death in African American women between 25-44 years of age in 2006 (Kaiser Family Foundation, 2009). The disproportionate rates of HIV related deaths and AIDS diagnoses in African American women are partially attributed to higher rates of non-adherence to ARV (Reynolds, 2004; Lucas, 2005).

Strict adherence to antiretroviral therapy is necessary to adequately suppress HIV viral replication and decrease the transmission of HIV and morbidity and mortality. According to the World Health Organization (WHO)(2003) adherence is defined as: “The extent to which a person’s behavior- taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider”(p.3). Adherence is a dynamic behavior that changes over time and is influenced by a matrix of interrelated factors (Reynolds, 2004). The complexity of medication taking behavior makes near perfect adherence difficult. African American women living with HIV are more likely to be non-adherent than white and Latina females (Ahdieh-Grant et al., 2005; Anastos et al., 2005; Cohen et al., 2004; Cook et al., 2002; Delahanty, Bogart, & Figler, 2004). The disparities in AIDS rates and deaths in African American women are largely considered a result of non-adherence. Unfortunately, the research exploring medication taking behavior in African American women living with HIV is scant. Thus, the purpose of this study was to explore medication taking behavior and determine predictors of medication taking behavior in African American women living with HIV.

### **Background and Significance**

Strict adherence to antiretroviral medication is necessary to optimize therapeutic benefits and decrease the transmission of HIV. Adequate HIV viral suppression decreases opportunistic infections, AIDS related deaths and the development and transmission of drug resistant HIV. Drug resistant strains of HIV are transmitted to both already infected and newly infected persons. In the United States, the prevalence of drug resistant HIV in

treatment naive persons increased from 3.4% in 1995 to 12.4% in 2000 (Little et al., 2002).

Several factors have been associated with medication taking behavior in African American women living with HIV. However, reliable predictors have not been identified (Sankar, Golin, Simoni, Luborsky & Pearson, 2006). Factors associated with non-adherent medication taking behavior include: being homeless in past year (Johnson, et al., 2003), number of pills, complexity of regimen, side effects (Gant & Welch, 2004; Lazo et al., 2007; Phillips et al., 2005), feeling unloved, HIV stigma (Edwards, 2006), negative medication beliefs (Malcolm, Ng, Rosen & Stone, 2003), dissatisfaction with their healthcare provider, lack of trust in their provider and lack of social support (Eversley, Isreli, Smith, & Kunwar, 1998; Gant & Welch, 2004; Sankar, Luborsky, Schuman, & Roberts, 2002; Trzynka & Erlen, 2004; van Servellen, Change, Garcia, & Lombardi, 2002) and low literacy (Kalichman, Catz, Ramachandran, 1999; Osborn, Paasche-Orlow, Davis & Wolf, 2007). Predictors of non-adherence in African American women include: having depressive symptoms (Anastos et al., 2005; Ahdieh-Grant et al., 2005; Cook et al., 2002), high childcare burden (Merenstein et al., 2009) injection drug use (Ahdieh-Grant et al., 2005) current crack, cocaine or heroin use and history of or current physical and/or sexual abuse (Cohen et al., 2004) and alcohol use (Lazo et al., 2007).

Several factors associated with greater adherence in African American women have been reported such as: simpler timing of medications; voucher payments and medication refills at methadone treatment centers (Gant & Welch, 2004); positive medication beliefs; being involved in support groups; receiving encouragement from family, social workers and nursing staff and being responsible for the care of others;

specifically children and grandchildren (Edwards, 2006; Gant & Welch, 2004; Tufts, Wessell, & Kearney, 2010). Spirituality positively influences adherent behavior in African American women living with HIV (Ironson & Kremer, 2009; Kremer, Ironson, & Porr, 2009; Knokle-Parker, Erlen, Dubbert, 2008; Tufts, et al., 2010). Women believe their spirituality helps them cope with side effects associated with their anti-retroviral therapy (Kremer, et al., 2009). Treating depression has also been found to predict more adherent medication taking behavior (Cotter, Potter & Tessler, ND). The arrays of factors related to medication taking behavior have been grouped into three categories: (a) medication related issues, (b) individual circumstances and (c) relationships, and will be presented in more detail in chapter 2.

A review of the HIV adherence research has revealed that most research examining adherence to medication in persons living with HIV has been atheoretical, qualitative and conducted with homogenous samples with little or no representation of African American women. Correlates of medication taking behavior presented in the absence of a theoretical framework are difficult to understand. Most theories utilized to examine health related human behavior are insufficient to explore medication taking behavior in African American women living with HIV because they do not address relationship type issues (instrumental, emotional and social supports) and individual circumstances like depressive symptoms and drug and alcohol use. The multitude and complexity of factors related to adherence are generally beyond the scope of more commonly utilized theoretical frameworks. Utilizing a framework capable of integrating multiple factors associated with medication taking behavior is necessary to fill the gaps in

the HIV related adherence research. The Reasonable Person Model (RPM) (Kaplan & Kaplan, 2003) is such a framework.

### **Theoretical Framework**

This study utilized the Reasonable Person Model (RPM) framework (Kaplan and Kaplan, 2003). The RPM was designed to provide a framework for identifying the kinds of environmental support that makes it more likely that individuals will behave in ways appropriate to their needs and circumstances. Kaplan and Kaplan (2006) suggested the RPM would be useful in identifying circumstances that help bring out the best in people. The premise of the RPM is that people have basic informational needs, regardless of their gender, race, ethnicity, socioeconomic status and education level. An individual is more likely to act in a reasonable manner when informational needs are met. Reasonable behavior is described as acting in a more cooperative, helpful and constructive manner (Kaplan & Kaplan, 2003). Kaplan and Kaplan's previous research has guided the identification of the three informational needs based constructs in the RPM: (a) understanding and exploration, (b) restoration, and (c) meaningful action (Kaplan & Kaplan, 1982; Kaplan & Kaplan, 1995; Kaplan & Kaplan, 2003; Kaplan & Kaplan, 2006).

#### *Assumptions*

The RPM framework assumes that humans can be reasonable and asserts that people are more patient, thoughtful and willing to work with others when the environment supports their basic informational needs. The RPM posits that when humans lack basic informational needs they exhibit unreasonable behavior and can display destructive, irrational and uncooperative actions. Informational needs are

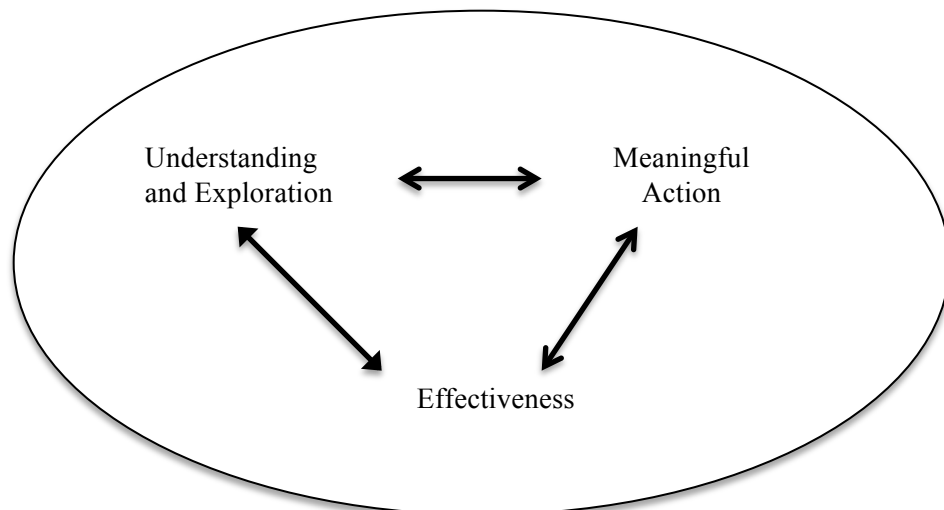
universal. While informational needs are universal the information needs to be individualized and context dependent. Informational needs are a delicate balancing act given that too much, confusing or inaccurate information can threaten both the ability to survive and the ability to be reasonable (Kaplan & Kaplan, 2003). This study used RPM constructs to better understand medication taking behavior in African American women living with HIV. The complete RPM has not been utilized in health behavior research previously. The effectiveness concept has been used to explore women's effectiveness during cancer treatment.

### *Theoretical and Operational Definitions of the RPM Constructs*

The three informational needs based RPM constructs are highly interrelated and include: (a) understanding and exploration, (b) effectiveness and (c) meaningful action. It is hard to act meaningfully without understanding, exploration can facilitate effectiveness. With increased effectiveness, we can be more effective in our actions (Kaplan & Kaplan, 2006). The interrelatedness of the three constructs is illustrated in Figure 1.1 (Kaplan & Kaplan, 2003).

Figure 1.1

### *Reasonable Person Model*





Both the theoretical construct definition and operational concept definition will be presented for each concept. The concept definitions were derived by a review of the adherence in African American women living with HIV literature.

Central to the understanding and exploration construct is the acquisition and comprehension of information. According to Kaplan and Kaplan (2006):

exploration is important in helping someone develop an internal model (or mental model) of a situation or activity or whatever it is one is trying to understand. By seeking answers to one's questions and finding out what one needs to know, the internal model is likely to be available and useful. (p.1)

The acquisition and comprehension of HIV information is related to medication taking behavior. Weiss et al. (2003) examined HIV knowledge and adherence and found participants who had greater knowledge had greater adherence to their HIV medications. The understanding and exploration construct was operationally defined as an individual's general HIV knowledge. HIV knowledge may include varied degrees of understanding related to the transmission of and protection from HIV, healthy/responsible behavior, consequences of non-adherence and side effect management. Building a useful internal model of HIV knowledge requires attention, which is seen as a scarce resource that also plays a central role in a person's effectiveness. Model building also requires listening and respect so that the individual's needs are acknowledged and respected. Note, the operational definition does not include exploration.

The effectiveness construct is comprised and defined by two concepts: (a) directed attention and (b) an intervention to replenish directed attention. The operational definition is the same as the theoretical definition.

There are two types of attention: involuntary attention and voluntary attention (now known as directed attention). Directed attention requires effort, is finite and readily

depleted. Involuntary attention is more automatic than directed attention. Involuntary attention is less goal-directed and controlled than directed attention. James (1892) (as cited in Kaplan & Berman, 2010) provides examples of stimuli that may evoke involuntary attention: “strange things, moving things, wild animals, bright thing, pretty things, metallic things, words, blows, blood etc” (p.88). Natural environments like parks, gardens and lakefronts are able to capture involuntary attention without reducing the capacity of directed attention and have proven to be useful in restoring the capacity of directed attention. However, it is likely nature is not the only source of restoration for directed attention. One could imagine other environments or activities that are pleasing and effortless as they would likely capture involuntary attention and replenish directed attention. What happens when directed attention is not restored?

When directed attention is not restored, directed attention fatigue results. Signs of directed attention fatigue (DAF) include irritability, inability to concentrate and feeling tired. These are signs most people would like to avoid. What depletes directed attention? While specific situations will vary among people, circumstances likely to deplete directed attention include: (a) “engaging in tasks with too little variation or spending too long on activity before changing” (Kaplan, 2001, p. 487), (b) situations in which there is insufficient or inappropriate information, (c) the need to run multiple models and (d) inadequate skill.

Persons suffering from directed attention fatigue are less likely to be effective in their actions and interactions with other people. Central to the meaningful action construct is the notion of effective actions and interactions with others. People experiencing directed attention fatigue, often experience a decline in their ability to be

effective in tasks and actions. Conversely, having adequate attention facilitates effectiveness and interactions with other people (Kaplan & Berman, 2010). The theoretical description of meaningful action is (Kaplan and Kaplan, 2006) describe meaningful action as:

activities that involve active participation. Being invited to engage in an activity can be a sign of respect, or the activity itself may bring respect. The activity may also make a difference, for instance, in one's own life, in one's community or in the environment. (p.1)

The adherence literature suggests that women who report participating in activities like taking care of others (children or grandchildren) or being involved in peer counseling report greater adherence than women who do not participate in similar activities (Gant & Welch, 2004; Gilbert & Wright, 2003). Additionally, social support is frequently cited as a factor related to medication taking behavior. The meaningful action construct is operationally defined as: an individual's perceived fit and level of participation with other people, their community and environment. Meaningful action implies being respected by others and doing things that one knows others value. Thus, one would expect that high meaningful action individuals are less likely to use drugs and alcohol and possibly less likely to suffer from depressive symptoms. It is also possible that depressive symptoms may impede one's ability to engage in meaningful action.

#### *Depressive symptoms*

Depressive symptoms were added to the framework and used to guide this study because they are prevalent in women living with HIV and have been reported to predict non-adherence in robust studies (Anastos et al., 2005; Ahdieh-Grant et al., 2005; Cook et al., 2002; Kanek et al., 2010). Rates of depression are higher in persons living with HIV than the general public (Neidig, Smith & Brashers, 2003; Kanek et al., 2010). Women

living with HIV reported greater symptoms of depression compared to males living with HIV (Wisniewski et al., 2005). The relationship between depressive symptoms and meaningful action is not well understood. This study assumed women who have less meaningful action will have greater depressive symptoms and depressive symptoms will decrease adherence to medication. Hagerty and Williams (1999) and Williams and Hagerty (2005) examined the relationship between sense of belonging and depression. The definition of sense of belonging is similar to the theoretical description of meaningful action. Both studies concluded sense of belonging had a direct effect on depression.

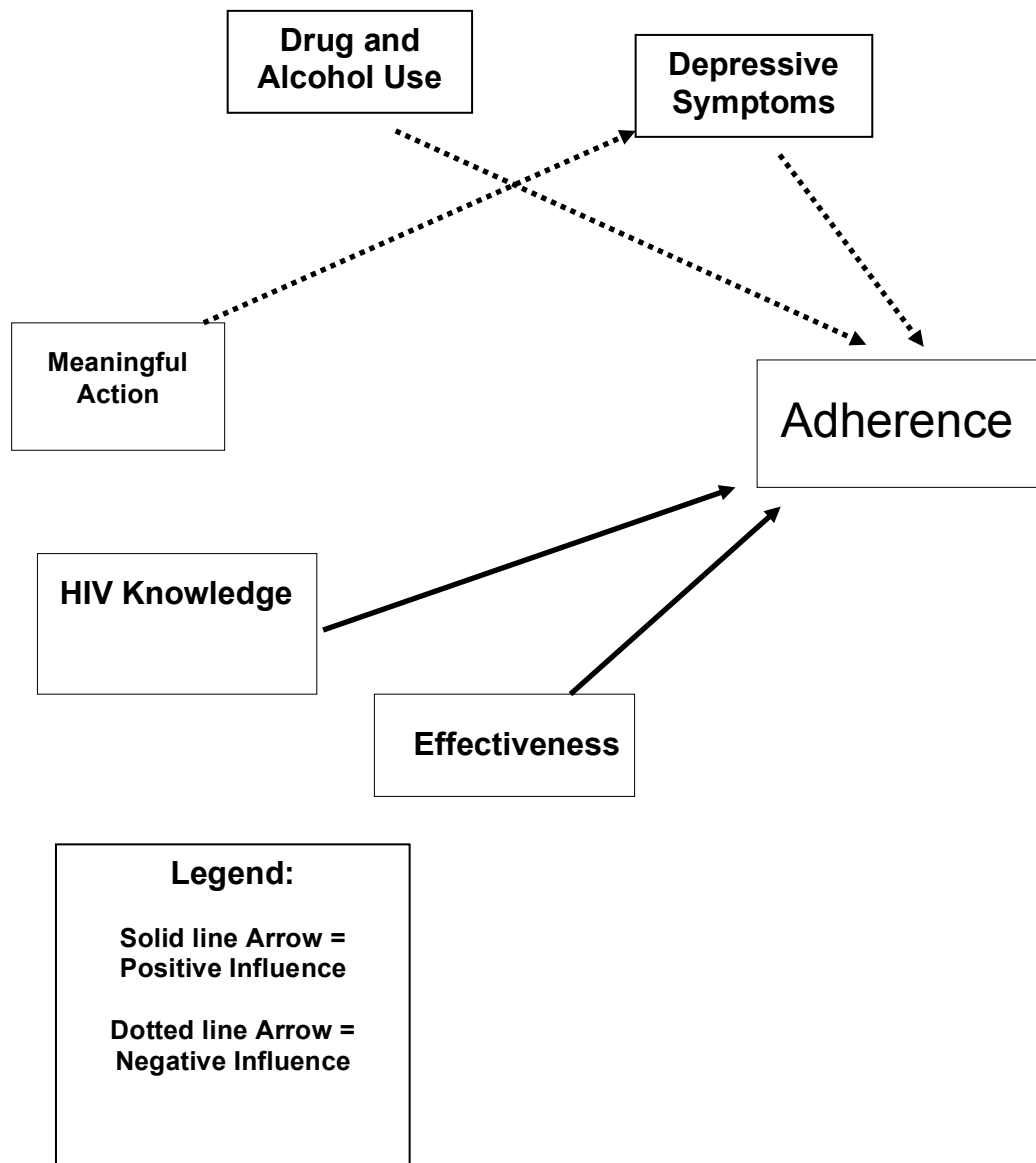
#### *Drug and alcohol use*

Drug and alcohol use was also added to the framework used in this study because it is repeatedly cited as a predictor of flawed medication taking behavior in African American women living with HIV (Ahdieh-Grant et al., 2005; Cohen et al., 2004; Lazo et al., 2007). Presumably, drug and alcohol use would influence an individual's ability to engage in meaningful action.

Figure 1.2 illustrates the model utilized in this study to explore medication taking in African American women living with HIV. Figure 1.2 includes the three RPM concepts and the added medication taking behavior, drug and alcohol use and depressive symptoms concepts.

Figure 1.2

*Study Framework*



*Relationships between concepts*

Each original RPM concept is related with the other concepts. Understanding and exploration has an interrelated relationship with effectiveness because an individual needs directed attention to facilitate understanding. Depleted directed attention can invite

exploration (in search of some type of restorative activity or of an understandable response to one's questions). Understanding and exploration has a reciprocal relationship with meaningful action because at some level, meaningful action requires exploration and understanding. People want to learn (understanding) how they can and should participate (meaningful action) and will explore (ask questions, watch other people, etc.) to increase their understanding. Meaningful action and restoration are reciprocal concepts because directed attention is necessary for people to be effective in their actions. Being effective in one's actions may also utilize less directed attention.

According to Cimprich and Ronis (2003), "Attentional fatigue can impair an individual's ability to acquire needed information about his or her disease and its treatment, to make treatment decisions, to adhere to complex regimens and to deal with painful losses and disruptions in daily living"(p. 285). Therefore, it is possible directed attention and HIV knowledge influences medication taking behavior.

The intersection of social value, respect, and feeling like one is making a difference in the world around them are components of meaningful action. Women who report caring for children and being a peer counselor are likely to have adherent medication taking behavior. Caring for children and being a peer counselor are examples of participation that allow an individual to exercise competence (gained from their understanding and exploration) and have feelings of having contributed to a larger goal.

People who are able to effectively utilize their understanding and be effective in their actions are less likely to have feelings of helplessness, hopelessness and low self worth. It is difficult to utilize understanding and act effectively without appropriate restoration. According to Kaplan and Kaplan (2006):

bringing out the best in people is more likely when their environments support exploration and understanding, enables meaningful action, and makes restorative experiences possible. Just as people who feel helpless, confused or exhausted are often not at their best, when these concerns are minimized people are considerably more like to be reasonable and constructive. (p. 3)

Presumably, unmet basic informational needs can negatively impact medication taking behavior in women living with HIV. Conversely, if their informational needs are being met, this could be exemplified by adherent medication taking behavior.

#### *Summary of Theoretical Framework*

The RPM is a midrange theory. Unlike other frameworks used to examine health related and medication taking behaviors, the RPM does not include specific variables like: socioeconomic status, education, beliefs, barriers, motivators, gender, race and health status. The RPM framework has not yet been utilized to examine medication taking behavior. Despite these limitations, the RPM constructs are compelling enough and sufficiently supported in the literature review to investigate as the antecedents of medication taking behavior.

#### **Specific Aims**

This descriptive, cross-sectional designed study employed survey methodology to examine medication taking behavior. The specific aims of this study were designed to examine predictors of medication taking behavior and relationships among the concepts of the Reasonable Person Model. Having a better understanding of predictors of medication taking behavior and the relationships of the concepts within the theoretical framework can provide insight for future intervention research. This study addressed the following aims:

1. Explore the internal models of HIV illness in African American women living with HIV.
2. Examine whether meaningful action, HIV knowledge and effectiveness predict adherence to medication taking behavior in African American women living with HIV.
3. Examine if depressive symptoms mediates the relationship between meaningful action and adherence and if meaningful action mediates the relationship between drug and alcohol use and adherence.

The findings from this study can determine predictors of medication taking behavior in African American women. Understanding reliable predictors of medication taking behavior will lay the foundation for future intervention research aimed to promote adherence in African American women living with HIV.



## **CHAPTER 2**

### **LITERATURE REVIEW**

In chapter 2, the HIV adherence and medication taking behavior research in African American women living with HIV has been synthesized and critiqued. Research that describes the relevance of Reasonable Persons Model (RPM) constructs in the lives of African American women living with HIV is described.

#### **Adherence to Medication**

Non-adherence to medication undermines the efficacy of medical care. Sub-optimal adherence to prescribed medications is common in chronic illnesses and not unique to persons living with HIV. According to Haddad et al., (2000) rates of adherence in the general public ranged from 15% - 93% and average around 50%. For persons living with HIV the rates of adherence have not been shown to be better than for other chronic illnesses (Reynolds, 2004), despite the known benefits of strict adherence to anti-retroviral therapy (Reynolds, 2004; Simoni, Frick & Huang, 2006). While adherence to medications is important in the treatment of all chronic illnesses, this study only examined adherence to antiretroviral medication (ARVs) in persons living with HIV.

#### *Measurement of Adherence*

Reliable measurements of adherence are necessary for clinical decision making and rigorous research. However, there is no gold standard for measuring adherence (Chesney, 2006; World Health Organization (WHO), 2003). In research, adherence measurement is influenced by a number of factors such as the definition of adherence

(appointment attendance or pill ingestion), the setting (clinical or research), cost, time, patient burden, and the interpretation of measurement results. The following section will discuss the pros and cons of several common measurement methods used in research and/or clinical settings.

Medication electronic monitoring devices (MEMS) are generally considered to be the most rigorous adherence measurement. MEMS circumvent the pitfalls associated with self report (i.e. social desirability bias, inaccurate recall) while providing real time measurement of adherence and the best correlation with virologic outcomes (Berg & Arnsten, 2006). However, electronic monitoring devices are costly and are not easily integrated with pill boxes and pocket dose practices (putting pills in pockets instead of taking pill bottle with them). Patients who utilize pill boxes or pocket doses due to stigma associated with HIV or life circumstances are not good candidates for electronic monitoring devices. Further, electronic monitoring devices are prone to measurement error by design; simply lifting the cover equates to a dose taken which may not always be true (Berg & Arnsten, 2006; Reynolds, 2004).

Laboratory measures of HIV viral RNA plasma and other markers of immune status are used as objective measures of adherence. Laboratory measurements avoid the errors associated with self-report and electronic measuring devices. However, pharmacokinetic assessments cannot be conducted without additional information including dose and time the medication was ingested and time of blood draw. This additional information does not typically accompany clinically based laboratory measurements. In addition, laboratory adherence measures are invasive for patients and costly (Berg & Arnsten, 2006). Further, patients may engage in more adherent

medication taking behavior if they anticipate their laboratory markers of adherence will be measured (Berg & Arnsten, 2006; Reynolds, 2004).

Another method, pharmacy refill records, offer supportive evidence of medication adherence, but also have several limitations. Medicine filled and picked up from a pharmacy does not ensure the medication was ingested. Furthermore, this measurement strategy assumes patients utilize the same pharmacy to fill medications (Berg & Arnsten, 2006; Reynolds, 2004).

Pill counts are another strategy for measuring adherence and can be conducted via telephone or in person. Pill counts conducted via telephone have been strongly correlated with HIV viral RNA (Kalichman, March 2008). Because of the necessary staff training and time consuming nature of pill counts (either in person or via telephone), financial viability is a significant limitation (S. Kalichman, personal communication, October 9, 2008). Additionally, the mechanism in which the data is provided to clinicians is more cumbersome than some self report strategies. In-person pill counts have shown moderate correlations with virologic outcomes (Berg & Arnsten, 2006). However, one limitation is persons may practice “pill dumping” or the act of patients discarding remaining medication in anticipation of the pill count (Reynolds, 2004; Berg & Arnsten, 2006).

Self-report is a commonly used measure of medication adherence. Simply asking patients about their medication taking behavior, pen and paper surveys, computer facilitated interviews, visual analogue scales and daily diaries are common self report strategies (Reynolds, 2004). Self-report techniques are convenient, require little time, have low patient burden and little to no associated monetary costs. Simoni et al. (2006) conducted a review of 77 studies that included self-reported adherence to anti-retroviral

medication published between 1996 and 2004. In this analysis, adherence assessed by self-report was significantly related to adherence assessed by other indirect measures such as EDM [electronic devices of measurement] and pill counts. Further, in 84% of recall periods, viral RNA was associated with adherence. These findings presented by Simoni et al. suggested that self-report strategies could be effective and reliable measures of adherence.

As seen above, multiple adherence measurement strategies exist. The WHO (2003) recommended considering several factors when measuring adherence but stated that ultimately, “strategies employed must meet basic psychometric standards of acceptable reliability and validity” (p.5). In a seminal article, Chesney (2006) presented a model of acceptable adherence measurement techniques based on the setting, endpoint of interest, and whether the measurement will be part of an assessment or intervention. According to Chesney, self-report is an acceptable measure of adherence in both research and clinical practice settings for either general HIV or adherence focused inquiries. Simoni et al., (2006) recommended that researchers and clinicians alike utilize self-report measures of adherence that have associations with indirect measures of adherence and viral HIV RNA. Based on these recommendations, the proposed study used the AIDS Clinical Trial Group (ACTG) adherence questionnaire, a self-report as a measure of adherence that has acceptable psychometric properties, correlated strongly with HIV viral RNA, had low patient burden, was inexpensive and easy to administer.

### **Medication Taking Behavior in African American Women with HIV**

“Adherence is increasingly understood as a dynamic behavior influenced by a matrix of interrelated factors that change over time” (Reynolds, 2004, p. 207). Most

theoretical frameworks are insufficient to explain and account for factors associated with medication taking behavior. Ickovics and Meisler (1997) acknowledged the absence of a theoretical framework in HIV adherence literature and suggested utilizing a broad conceptual framework capable of capturing the varied factors associated with medication taking behavior. Medication taking behavior in African American women living with HIV can be partially understood using the concepts in the RPM.

*Factors Associated with Medication Taking Behavior*

As shown in Table 2.1, factors associated with medication taking behavior can be classified into three categories consistent with constructs in the RPM: (a) understanding and exploration (b) restoration and (c) meaningful action.

Table 2.1

*RPM Themes of Medication Taking Behavior*

	Understanding and Exploration	Restoration	Meaningful Action
Barriers to Adherence	Negative medication beliefs, HIV knowledge	Forgetting, sleeping through doses, complicated regimens	Dissatisfaction with healthcare provider, lack of trust in healthcare provider, lack of social support, depressive symptoms, homeless in past year, spirituality, stigma, having children living in the home and having perceived level of high care burden with children
Facilitators to Adherence	Positive medication beliefs, HIV knowledge	Simplify timing of meds	Support group involvement, encouragement from family, social workers and nursing staff, responsibility for the care of others, treatment of depressive symptoms, spirituality

### *HIV Knowledge*

Understanding was conceptualized as an individual's general HIV knowledge. Medication beliefs and HIV knowledge demonstrate an individual's understanding of their disease and are informed and shaped by a number of influences (e.g. media, friends, family, healthcare provider). Beliefs and knowledge influence medication taking behavior, with positive medication beliefs positively associated with adherent behavior (Malcolm et al., 2003) and negative medication beliefs positively associated with non-adherence (Barclay et al., 2007; Roberts & Mann, 2000; Viswanathan, Anderson, & Thomas, 2005).

Prior research has shown that African American women living with HIV have more negative medication beliefs than other women. Schrimshaw et al. (2005) conducted focused interviews with women from either the pre highly active anti-retroviral therapy (HAART) (1994-1996) or HAART (2000-2003) eras. The purpose was to examine attitude changes regarding anti-retroviral therapy. Women in the pre HAART era reported more negative beliefs about medication, fewer perceived benefits and more intolerable side effects than women in the HAART era. African American women in both eras held more negative beliefs and fewer perceived benefits of therapy than white and Puerto Rican women. Although adherence was not assessed in this study, the finding of greater negative beliefs in African American women may contribute to less adherence than white or Latina women (Ahdieh-Grant et al., 2005; Anastos et al., 2005; Cohen et al., 2004; Cook et al., 2002; Delahanty et al., 2004; Johnson, et al., 2003; Burke-Miller, et al., 2006).

HIV knowledge has also been shown to positively influence medication taking behavior. Weiss et al. (2003) examined HIV-related knowledge and medication adherence in 997 persons living with HIV/AIDS. Forty-two percent of the subjects were female and nearly half were African American (n = 478). HIV knowledge was assessed by a five item, true or false questionnaire. Adherence was measured with the 3 day self report Adult AIDS Clinical Trials Group Adherence Questionnaire. Results showed that nearly 20% of both male and female subjects answered at least two knowledge questions incorrectly. In addition, HIV knowledge was significantly and positively associated with adherence.

Results from two large surveys provide further evidence of limited understanding of general HIV knowledge in persons living with HIV. Baxter (2006) highlighted the knowledge gap between providers and patients. Survey results revealed 91% of physicians reported being very concerned with HIV drug resistance but only 54% of patients were as concerned. Further, 65% of patients reported that their physician was their primary source of drug resistance information yet, only 25% of physicians provided educational materials regarding drug resistance.

Results from the AIDS Treatment for Life International Survey (ATLIS) were consistent with the theoretical underpinnings of the understanding and exploration construct in the RPM and uncover a lack of basic HIV knowledge. ATLIS was administered to 2,555 persons living with HIV in 18 countries. Results affirm a lack of basic HIV knowledge and a need for additional HIV education. Of the 2,555 respondents, 69% reported that they wished they knew more about HIV disease and treatment options. Respondents were asked to describe how HIV drug resistance



develops. Only 17% accurately answered this question and 54% answered incorrectly or did not know the answer (Mascolini & Zungia, 2008).

Results from these studies suggested a lack of HIV knowledge in persons living with HIV. This is problematic because as Weiss et al. (2001) concluded: HIV knowledge influences medication taking behavior. Moreover, this lack of understanding about HIV could deplete directed attention, which is necessary for making health care decisions such as medication adherence. Kaplan (2001) describes four situations that readily deplete directed attention. Two of the four are evident in the aforementioned studies: (a) situations in which there is insufficient or inappropriate information, and (b) inadequate skill.

Conclusions from the literature review are that linkages exist between medication beliefs, HIV knowledge, and medication adherence. However, a gap in the literature exists because few studies have examined the relationships between HIV knowledge, directed attention and adherence. This study addressed this gap.

### *Effectiveness*

According to Cimprich and Ronis (2003), “Attentional fatigue can impair an individual’s ability to acquire needed information about his or her disease and its treatment, to make treatment decisions, to adhere to complex regimens...”(p. 285). Directed attention is a concept within the effectiveness construct, and was conceptualized as an individual’s capacity for attention that requires effort. Directed attention is a finite resource. Depletion of it results in mental fatigue (directed attention fatigue), an inability to concentrate, and feelings of tiredness (Kaplan & Kaplan, 2006). Taking medication as

prescribed requires effort, and people suffering from an inability to concentrate would have less adherent behavior.

Harmon, Barroso, Pence, Leserman and Salahuddin (2008) examined demographic and illness related variables associated with HIV related in fatigue in 128 persons. The sample was predominately African American (n=84) but few women (n=44) participated. Fatigue was negatively associated with participants' ability to think quickly, perform household activities, plan activities and think clearly. Participants reported difficulty concentrating; increased drowsiness; losing patience and interference with work, family and social life as the worst consequences of fatigue. African Americans scored higher than Whites on fatigue intensity though this was not statistically significant. However, the impact of fatigue on overall functioning as reported in African Americans compared to whites was statistically significant ( $p < .05$ ). Participants who reported taking antidepressants tended to score higher on fatigue intensity ( $p < .10$ ) and impact of fatigue on overall functioning ( $p < .05$ ).

Complexity of antiretroviral regimens and forgetting/sleeping through doses are factors positively associated with non-adherence (Erlen et al., 2002; Gilbert & Wright, 2003; Phillips et al., 2005; Roberts & Mann, 2000; Sankar et al., 2002; Schrimshaw et al., 2005; Trzynka & Erlen, 2004). Erlen et al., (2002), conducted a secondary data analysis of data collected from 61 women (36% African American) and found that reasons for non-adherence included forgetting to take medication (n=24), not carrying medications when participants went out (n=21), falling asleep (n = 14) and undesirable side effects (n = 9). Forgetting is a sign of directed attention fatigue (Kaplan & Kaplan, 2002).

Since some of the known correlates of medication taking behavior appear to be influenced by directed attention, this study examined effectiveness (directed attention and an intervention for improving directed attention) and adherence.

### *Neurocognitive Changes and Directed Attention*

Declines in neurocognitive functioning could impede directed attention efforts. Directed attention and working memory make the same demands on cognition and can be affected by neurocognitive changes. Persons living with HIV can develop neuropsychological deficits ranging from subtle, sub-clinical, mild to moderate deficits, (identified only by sensitive neuropsychological tests) to more debilitating HIV associated dementia (HAD). Typically, cognitive impairment progresses as the disease progresses. However, cognitive deficits also occur in otherwise healthy persons living with HIV (Wilkie et al., 2000; Chang et al., 2001). According to Chang et al. (2001), “Typical neuropsychological deficits in HIV patients include decreased sustained attention, mental flexibility, general motor speed and memory. In particular, working memory may be affected in these patients”(p.1001).

Little is known about the rate and extent of neuropsychological deficits attributable to HIV infection. Munoz-Moreno et al. (2008) examined neuropsychological deficits in three groups of patients. The primary groups of interest were persons with fewer than 200 CD4 cells/ml and more than 200 CD4 cells/ml. Significant functioning differences were found in the two groups. Neurocognitive impairments were more prevalent in persons with fewer than 200 CD4 cells/ml. Additionally, the two groups had statistically significant differences in functional attention and working memory (measured by digit span backward,  $p = .032$ ) and executive functions (measured by Trail-

Making test part B,  $p = .020$ ) with the group of persons with greater than 200 CD4 cells/ml having greater functioning.

In a study by Failde-Garrido, Alvarez and Simon-Lopez (2008), differences in neuropsychological abilities and deficits were examined in 57 HIV seropositive men, 31 seropositive women, 18 seronegative men, and 16 seronegative women. Subjects underwent a battery of common neuropsychological tests including Trail-Making test, Toulouse-Pieron test, Babcock Story Recall test, and all components of the Wechsler Adult Intelligence Scale. No statistically significant differences in sociodemographic and clinical variables were found among the four groups. Seropositive women experienced deficits in attention/psychomotor speed, verbal memory tests, visual memory and abstract reasoning. Statistically significant differences were found between the neuropsychological impairment of seropositive and seronegative subjects. Seropositive women had a statistically significant impairment rate greater than seronegative women ( $\chi^2 (1) = 8.73; P < .005$ ) which was greater than the difference found in seropositive and seronegative men ( $\chi^2 (1) = 14.3; P < .001$ ). If women living with HIV have a greater rate of cognitive impairment, a more close examination of attention in women living with HIV is warranted.

Barclay et al., (2007) examined the relationships of age, adherence, health beliefs, self efficacy and neurocognitive status in 185 HIV positive persons. Females comprised 22% of the sample size and 69% of these women were African American. Poor adherence was twice as high in younger participants as older participants (68% and 33% respectively). Results from binary logistic regression revealed decreased neurocognitive functioning was the only independent predictor of poor adherence in older participants.

This study utilized a battery of neuropsychological tests and total score as an independent predictor of adherence. Attention/working memory was a component of the neuropsychological battery of tests. Individual components of neuropsychiatric testing were not regressed on adherence.

As a result of antiretroviral therapies (ARV), HIV infected individuals are living longer, healthier lives and are less commonly affected by HIV associated dementia (HAD). In contrast, milder forms of cognitive impairments are becoming more prevalent. These mild impairments are thought to be partially attributed to persons living with the virus longer and common impairments typically associated with aging. Chang et al. (2008) examined magnetic resonance imaging (MRI) of the brain during visual attentional tasks in three groups of men: Seronegative (control group), seropositive receiving ARVs and seropositive ARV naïve (people whom have never ingested anti-retroviral therapies). Changes in MRI suggested:

...chronic ARV treatments may lead to greater requirement of the attentional network reserve and hence less efficient usage of the network and less practice effects in these HIV patients. As the brain has a limited reserve capacity, exhausting the reserve capacity in HIV + ARV would lead to declined performance with more difficult tasks that require more attention. (p.95)

These findings suggest the antiretroviral medications necessary for survival could result in directed attention fatigue. This directed attention fatigue may impact an individual's ability to take their medicine as prescribed. The neurocognitive changes associated with HIV provide further support for the importance of examining directed attention and medication taking behavior. This is a gap in the HIV adherence literature.

Directed attention fatigue can be replenished by restorative environments and activities. There is robust literature examining and providing evidence for the

relationship between restoration and directed attention (Kaplan & Berman, 2010). Natural environments and green spaces are known exemplars of restorative environments (Kaplan & Kaplan, 2001). A disproportionate number of African American women living with HIV reside in urban environments (Gilbert & Wright, 2003). Urban environments typically have less nature and therefore, women have less exposure to restorative environments. The literature suggests that African American women living with HIV have less exposure to restorative, natural environments and consequently are more at risk for persistent depletion of directed attention and mental fatigue. Not only do urban environments lack natural environments necessary for replenishing directed attention, they could be a source of social disorganization that may undermine meaningful action. Latkin and Curry (2003) investigated the impact of neighborhood disorder in 818 men and women living in an inner city. The authors suggested that social disorganization found in inner cities may impede the establishment and maintenance of social relations.

#### *Spirituality as a source of restoration*

This study was designed presupposing that spirituality could be a source of restoration for directed attention in African American women. The premise of restorative activities is that they be effortless and enjoyable. Results from research examining spirituality and relationships with God in African American women living with HIV has concluded: 1) spirituality/ relationship with God is an important aspect of their lives and 2) spirituality is associated with better treatment success and improved adherence to medications (Casarez & Miles, 2008, Konkle-Parker, Erlen, & Dubbert, 2008; Kremer et al., 2009). Damlida, Holstad, Dilorio and Laderman (2009) examined spiritual well-being, depressive symptoms and immune status in a predominately African American

sample of 129 women. The spiritual well-being scale was utilized to assess religious and existential aspects of spirituality. Significant positive associations were observed between religious well-being ( $r = .22, p < .05$ ) and spiritual well-being ( $r = .24, p < .05$ ) with CD4 absolute counts and percentages. Interestingly, depressive symptoms were not significantly associated with CD4 absolute counts or percentages. However, a significant inverse relationship was observed between spiritual and religious practices and depressive symptoms.

#### Meaningful Action

Several already identified correlates of medication taking behavior in African American women living with HIV are associated with meaningful action. For the purposes of this study, meaningful action is described as an individual's perceived fit and level of participation with other people, their community and environment. Meaningful action also includes gaining the respect of others. This could include respect (or lack thereof) on the part of healthcare providers. Presumably, there is a relationship between social supports and having a sense of fit and participation. Factors that promote meaningful action and adherence include being involved in support groups; receiving encouragement from family; receiving support from social workers and nursing staff; and being responsible for the care of others; specifically children and grandchildren (Edwards, 2006; Gant & Welch, 2004). Several studies have reported that African American women report dissatisfaction with and lack of trust in their provider, lack of social support, and being homeless in the past year (Eversley et al., 1998; Gant & Welch, 2004; Mallory et al., 2003; Sankar et al., 2002; Trzynka & Erlen, 2004; van Servellen et

al., 2002) as barriers to adherent medication taking behavior. These factors are likely to undermine meaningful action.

*Meaningful action as facilitators to adherence*

Many studies have examined social support and medication taking behavior. Social support can be considered component of the meaningful action concept. In a study conducted by Gant and Welch (2004), face-to-face interviews (n=90) and focus groups (n=30) were conducted with African American women living with HIV to identify factors associated with medication adherence. Positive influences included participation in support groups; encouragement from family members, social workers, and nursing staff; and concern for and daily care of their children. According to Gant and Welch, “Women remark that such support often helps them stay on track”(p. 74). Women reported that their children provided motivation for them to take their medication. Participants expressed a desire to be there for their children, to be able to watch them grow and to provide for them. Raising children is an example of meaningful action because women feel that they are participating in and contributing to a larger goal.

Similarly, African American women reported that social support from friends and family along with having young children facilitated adherent medication taking behavior (Edwards, 2006). Women who report receiving social support from friends and family are likely to have a strong sense of perceived fit, while having young children likely provided a sense of participation and meaningful action for women.

Malcolm et al. (2003) provides another example of meaningful action in the lives of African American women living with HIV. In this study, semi-structured interviews were conducted with 28 men and 16 women (39% African American). Adherence was



measured by self report and divided into two categories: excellent (90-100% adherence) and less than perfect (all other adherence less than 90%). Individuals who were categorized into the excellent adherence category (90-100% adherence) were more likely to have undetectable viral loads than those who were classified as having suboptimal adherence. Individuals who reported excellent adherence were also more likely to have disclosed their HIV status to friends and family and to have reported receiving strong social support. It is likely that individuals who have family support have some sense of “fit” in their family, thus providing support for medication adherence.

Simoni et al. (2006) explored social support and medication adherence in a sample of 136 participants (46% African American and 45% women). In contrast to Malcolm et al. (2003), results from bivariate analysis and structural equation modeling suggest that social support did not directly impact adherence or viral load, but indirectly impacted these variables through less negative affect, greater spirituality and self efficacy to adhere. These findings can be explained in the context of the RPM. Social support increases a person’s interactions with others. Having higher levels of meaningful action may positively affect directed attention. It is plausible that the spirituality experience not only served as a source of social support, but also as a source of restoration for directed attention (Ouellette, Kaplan, & Kaplan, 2005).

Increasing a social support network along with, having a sense of fit and participation (i.e. meaningful action) are common themes in the transformative experiences described by Gilbert and Wright (2003). Transformative experiences were defined as experiences of daily living or characteristics that had a dramatic and positive change on a woman’s life. Of the ten listed experiences, five paralleled the meaningful

action construct. These included: (a) achievement of family reunification, (b) if non-spiritual, becoming spiritual, (c) if a high school drop-out, working toward or obtaining a GED, (d) if unemployed, becoming employed or actively seeking employment and (e) if socially unmotivated, having moved into volunteer activities. While medication taking behavior was not assessed in this study, each of these five transformative experiences could enhance social support, a known factor associated with greater medication adherence.

Another example of fit and participation is evident in the role of peer counselors. Gilbert and Wright (2003) report, “Of particular importance is the desire for many of the women in the study to act in collective ways, to share their experiences of living with HIV as peer counselors or through advocacy work...” (p.74). Women who participate in peer counselor roles are more likely to be adherent than women who are not peer counselors (Gant & Welch, 2004; Gilbert & Wright, 2003).

Social support, acting in collective ways with others and having a sense of fit and participation in one’s environment are important factors for African American women that may support adherent medication behaviors. Feaster, Brincks, Mitrani, Prado, Schwartz and Szapocznik (2010) conducted a secondary data analysis from data generated from a randomized clinical trial testing the efficacy of structural ecosystems therapy for medication adherence in African American women living with HIV. Therapists in Structural Ecosystems Therapy (SET) assist individuals to restructure maladaptive interpersonal interactions within families and other systems (e.g. health care providers) to form positive interaction and to promote healthy relationships in and outside of the family. This study followed 156 African American women at three month

intervals over 18 months. Women either received SET, person center conditions (PCA) or a community control condition (CC) as the intervention. Women who received the SET intervention significantly improved their adherence over time compared to women who received the PCA. The results of this study provide some support for the notion of the importance of family relationships and the impact of healthy relationships on medication taking behavior in African American women living with HIV.

### *Depressive Symptoms*

Another barrier to medication adherence in African American women is depressive symptoms. Women living with HIV report greater symptoms of depression compared to males living with HIV (Wisniewski et al., 2005) which undermine adherent medication taking behavior (Ahdieh-Grant et al.; Anastos et al., 2005; Cook et al., 2002; Kanek et al., 2010). Treating depressive symptoms promotes adherent medication taking behavior (Anastos et al. 2005; Cook et al., 2002; Cotter, Potter, & Tessler, ND; Yun, 2005). Cook et al., (2002) examined the effects of depressive symptoms and mental health quality of life on utilization of HAART in 1668 women enrolled in the Women's Interagency Health Study (WIHS). Data was collected biannually from 1996 through 1998. Depression was measured by the CES-D. Overall, women in the WIHS reported higher depressive symptoms compared to the general public and chronically ill population. Higher reported depressive symptoms were associated with being non-White, having a history of IV drug use, having viral loads greater than 200,000 copies/mL, currently using drugs and/or alcohol, and having no college education. A longitudinal random effects logistic regression model was used to determine if depressive symptoms influenced women's probability of being on HAART. Utilization of mental

health services and demographic variables were controlled. Women with CES-D scores indicating probable depression were significantly less likely to report HAART utilization. In other logistic regression models, being African American ( $p < .001$ ), having a history of injection drug use ( $p < .05$ ) and current alcohol and/or drug use ( $p < .001$ ) were significantly associated with reports not using HAART after controlling for depressive symptoms and mental health services utilization.

Depressive symptoms have also been associated with discontinuing HAART. Ahdieh-Grant et al. (2005), utilized the WIHS data to explore factors and trends associated with the discontinuation of HAART. Data from 936 HIV seropositive women were examined at three consecutive time points. Factors with univariate P values less than 0.100 in any of the three time periods were included in the multivariate models for each time period. Multiple variable Cox proportional hazards model concluded depressive symptoms were significantly associated with an increased risk of discontinuing HAART. In calendar stratified analyses, African Americans (RH = 4.11) relative to Whites and injection drug use (RH = 4.15) were significantly associated with stopping HAART in the first calendar year. Being African American (RH = 2.86) was also significantly associated with HAART discontinuation in the second calendar year. No factors were significantly associated in the third calendar year.

Depressive symptoms have been associated with poor virologic response, increased likelihood of immunologic failure and incidence of AIDS defining illness, each being a consequence of non-adherence. Anastos et al., (2005) examined virologic suppression and failure, immunologic failure, AIDS defining illnesses, deaths and HAART use in 961 women who participated in the WIHS. The primary exposure of

interest was three groups of self defined women: African American, White, and Hispanic. Cox regression and univariate models were used to assess the differences in immunologic, virologic and clinical outcomes. African American women were less likely to survive than White and Latina women. Depression (CES-D score of 16 or greater) was found to be significantly associated with poor virologic response, increased likelihood of immunologic failure, incidence of AIDS defining illnesses and higher risk of death (not AIDS related). Independent of depression, race was the strongest predictor of discontinuing HAART with White women less than half as likely as African American (RH = 0.43, P < .001) or Hispanic women (RH = 0.32, P < .001) to discontinue HAART. The higher prevalence of reported depressive symptoms and depression did not explain the higher rate of HAART discontinuation in African American and Hispanic women. Therefore, depression and depressive symptoms cannot be the sole factors for African American women stopping HAART.

As the aforementioned studies demonstrate, barriers to meaningful action, such as lack of social support and depression, can have detrimental effects on medication adherence behavior in African American women living with HIV. Additional research is needed to explore the relationships between meaningful action, depressive symptoms and medication taking behavior in African American women living with HIV.

#### *RPM Concepts and Adherence*

The RPM has not been used in adherence research. However, in studies conducted by Jones et al. (2003, 2007), underpinnings central to each of the three main RPM concepts are included. Jones et al. (2003) and Jones et al. (2007) conducted intervention studies utilizing cognitive-behavioral stress management/expressive

supportive therapy in minority women living with HIV. Women in the intervention group increased their self-reported medication adherence compared to the control group (Jones et al., 2003). Group conditions showed more favorable outcomes than did individual based interventions (Jones et al., 2007). These findings suggested that medication knowledge and group strategies should be considered for future adherence interventions in women living with HIV. The recommendation of utilizing group strategies is not surprising given that this venue may serve as a source of social support, which is associated with more adherent medication taking behavior.

Though it was not measured, the Jones et al. (2003, 2007) studies utilized cognitive behavioral stress management that may have indirectly or directly influenced directed attention. According to Kaplan (2002), directed attention fatigue is commonly and inappropriately referred to as stress. If the stress management intervention provided rest for directed attention then medication knowledge strategies would be better received and potentially be more effective because people would have more available attention to expend on understanding.

#### *Summary of Medication Taking Behavior Literature Review*

The review of HIV medication adherence in African American women literature is scant and has revealed several gaps and criticisms. Several correlates of medication taking behavior have been identified, yet few modifiable and reliable predictors of medication taking behavior have been identified in African American women living with HIV (Prosser, 2006; Sankar et al., 2006; Simoni et al., 2006). The lack of reliable predictors of medication adherence can be partially attributed to the atheoretical nature of

adherence research and few quantitative studies of solely African American women (Prosser, 2006).

One major gap in the HIV adherence literature is the lack of inclusion of African Americans. Most HIV adherence research has been conducted in homogenous samples of White, homosexual men. Research that has been conducted with larger, more diverse samples of persons living with HIV generally include a small percentage of African American women. This is problematic because findings have not produced sufficient statistical power to provide meaningful information about African American women.

Several correlates of medication taking behavior (depressive symptoms, current drug or alcohol and being black) have been identified by analyzing data from the Women's Interagency HIV Study (WIHS), the largest study of HIV seropositive women to date. The WIHS explored the natural history of HIV infection in women in a five year, multisite, prospective cohort study enrolling 2059 HIV seropositive women between October 1994 and November 1995. While the WIHS provides rich data in the study of seropositive women, its greatest limitation is that it did not utilize a theoretical framework. Interpreting correlates of adherence in the absence of a theoretical framework is difficult. Had the WIHS cohort study used theoretical framework to explore adherence and other behaviors, the findings would have been more interpretable and possibly provided a basis for the development of interventions aimed at promoting adherence in women.

### **Chapter Summary and Research Direction**

There is a need for an overarching theory of adherence that integrates findings on adherence correlates (Simoni et al., 2006). The Reasonable Person Model (RPM) has not

been used to examine medication taking behavior yet it appears that factors associated with medication taking behavior in African American women living with HIV can be conceptualized within the theoretical underpinnings of the RPM. Hence, testing the hypothesized relationships between the RPM constructs and concepts relevant to medication taking behavior (e.g. depressive symptoms and drug and alcohol use) and the significance of these relationships and medication taking behavior is an appropriate first step to guide future adherence intervention research.



## **CHAPTER 3**

### **METHODOLOGY**

#### **Introduction**

Chapter three will discuss the study design, sample, procedures and measurements/instruments. This chapter will also discuss the reliability measures of each measure/instrument.

#### **Design**

In this descriptive, cross sectional study, 18-60 year old African American women living with HIV (N = 110) were recruited from an HIV clinic associated with a county hospital and from the local community in a metropolis in Minnesota. Data collection occurred at one point in time.

#### **Setting and Sample**

##### *Setting*

African American women living with HIV were recruited from an HIV care clinic embedded in a large, county and teaching hospital that serves five states in the Midwest. The clinic is a site for numerous federal and industry sponsored HIV research projects and was previously a sub-site for the University of Minnesota AIDS Clinical Trial Group. The clinic provides HIV care to nearly 1500 individuals annually, making it one of the largest HIV care clinics in the Midwest. Over 20% of the persons receiving care from the PCC are African American women.

### *Sample*

Purposive and snowball sampling was used to recruit 110 African American women from the HIV clinic and the local community in the Midwest. Women were eligible to participate if they were between the ages of 18 – 60 years, had been prescribed at least one HIV antiretroviral medication, self identified as African American and female at birth and were able to speak, read and write in English. Women were excluded if they had a diagnosis of HIV associated dementia (HAD) and could not identify an HIV provider. No women were excluded from participating in the study. The women's ages ranged from 22-60 years with a mean of 43.5 (*SD* 9.72) years.

### **Data Collection Procedures**

The Institutional Review Board at the University of Michigan and the Human Subjects Review Committee for the health system associated with the clinic approved procedures for this study. Written informed consent was obtained from all participants prior to the study visit. Data collection included review of inclusion/exclusion criteria, digit span backwards, cognitive map exercise and the study questionnaire.

### *Procedures for Women*

The Principal Investigator (PI) and research assistants (RA) recruited women from waiting and exam rooms in the clinic. Research assistants were trained by the PI and had completed necessary requirements to participate in conducting research by the institution where the study was conducted. Providers and clinic staff referred women to the PI. To minimize clinic burden, the PI posted flyers and provided study information packets (including the purpose of the study and informed consent forms) in the waiting and exam rooms. The PI also contacted other clinics and community agencies that

provide resources for African American women living with HIV to post study flyers in waiting rooms and on informational boards.

Once the women indicated that they were interested in learning more about the study or participating in the study, the PI or RA explained the purpose and procedures of the study to the women. Women were escorted to a private consult room or met with the PI or RA in a clinic exam room. Women were given a consent form to read and provided with an opportunity to ask questions. First, digit span backward was administered per protocol. After completion of the digit span backward test, the PI or RA gave the questionnaire to the woman to complete. The cognitive conceptual map exercise and different scales within the questionnaire was explained and women were requested to place their completed questionnaire in the study folder when they were finished. The woman was left alone to complete the questionnaire. The PI or RA waited outside of the consult or exam room and periodically entered to provide the woman an opportunity to ask any questions or seek clarification. Each folder had a coded number on the outside of the folder which served as the woman's unique study number. No identifiable information was collected from questionnaire. Women received \$20.00 after completing the study visit.

### **Measures**

This section will discuss the pretesting of patient measures and will describe the measures used to collect data in this study.

#### *Pretest of Measures and Assessing for Feasibility*

Data collection procedures and questionnaires were pre-tested with three African American women living with HIV. The purpose of the pretesting was to assess for clarity

of content, completeness and feasibility. African American women between the ages of 18-60 years old (n =3) were recruited from the clinic. All three women completed the study visit in less than 60 minutes. None of the women had suggestions for improvement or needed clarification of instructions or questions. Therefore, study procedures and questionnaire were not modified (refer to appendix for complete questionnaire).

### *Concept Measures*

All theoretical concepts based on the Reasonable Person Model and depressive symptoms, drug and alcohol use and related empirical measures, including a reliability measure for each scale ( $\alpha$ ), are listed in Table 3.1. The following section will discuss each measure assessed and its operational definition.

Table 3.1

*Descriptives for Scaled HIV Knowledge, Sense of Belonging, Mattering to Others, Spiritual Well-Being, Digit Span Backwards, Depressive Symptoms, Drug and Alcohol Use and Adherence for Women*

Measure	N	Range	Mean (SD)	# of scale items	$\alpha$
HIV Knowledge					
HIV Knowledge	108	11-44	35.02 (5.90)	45	.83
HIV Treatment Knowledge	110	10-21	16.79 (2.40)	21	.49
Meaningful Action					
Sense of Belonging	110	18-72	53.33 (11.38)	18	.93
Mattering to Others	110	6-20	17.24 (3.43)	5	.89
Effectiveness					
Spiritual Well-Being	110	57-120	89.11 (16.71)	20	.86
Digit Span Backwards	109	2-8	4.49 (1.23)	n/a	n/a
Depressive Symptoms	110	0-49	22.98	20	.90
CES-D			(12.59)		
Drug and Alcohol Use					
two-item conjoint screening tool	109	0-3	.62 (.85)	3	.81

### *Adherence*

Adherence was operationally defined as the weighted total index score from the AIDS Clinical Trial Group adherence questionnaire (Reynolds et al., 2007). The questionnaire is comprised of seven questions asking about number of missed doses (yesterday, two days ago, three days ago and four days ago), how closely the patient followed the medication schedule, how closely the patient follows medication taking instructions, the last time any medication was missed and whether any medication was

missed last weekend. Reynolds, et al. (2007) conducted a series of statistical analyses from ACTG questionnaire data in an attempt to optimize the measurement of the ACTG adherence questionnaire. The results of principle component analysis resulted in the development formula that calculates a weighted adherence score from 0-100 . The formula is as follows:

$$\text{Adherence} = 100 \times \{[0.65 + (2.15 \times \text{adh1day}) + (2.21 \times \text{adh2day}) + (2.07 \times \text{adh3day}) + (1.99 \times \text{adh4day}) + (0.37 \times \text{Follwsch}) + (0.36 \times \text{Instructions}) - 0.13 \times \text{Lastskip}]\} / 11.99\}.$$

This formula was entered into SPSS (Version 14.0, SPSS Inc., Chicago, IL) and each woman's individual item response was entered in as the variable. This formula provided a weighted total adherence score between 0-100 for each woman.

#### *Internal Models of HIV*

Internal models of HIV were assessed by the Conceptual Content Cognitive Map (3CM) exercise. The 3CM cognitive map technique was utilized to assess the women's perceptions of their HIV/AIDS illness. The 3CM cognitive map technique assesses what one thinks about a related topic (Kearney & Kaplan, 1997), like HIV. Women were given a sheet of paper with 20 words and phrases listed in a left column and a blank column on the right. Women were prompted by the following phrase, "I want you to think about telling someone about living with HIV who knows nothing about HIV. What would you tell them? What would be important for them to know? If you would use the word or phrase, circle it and on the right side place a positive or negative sign indicating how you feel about it." These lead in questions were designed to provide a "blank canvas" for the women to paint their picture about living with HIV. Words and phrases were determined by expert opinion of health care providers and social workers working with persons living with HIV. Examples of words were: death, drug resistance, skipping doses,

sex, second chance, stigma, and God. Had the woman been asked specifically about adherent behaviors, their responses may have been biased to include adherence or discussions about medication taking when in fact, these concepts may not be central to their experience living with HIV. Women were also encouraged to “free write” in available spaces with many women taking advantage of this opportunity to further explain or tell their story.

### *HIV Knowledge*

The theoretical concept of understanding and exploration was assessed by the two instruments: the HIV Knowledge Questionnaire (HIV-KQ-45) (Carey, Morrison-Beedy & Johnson, 1997) and the HIV Treatment Knowledge Scale (Balfour et al., 2007). The understanding and exploration concept was operationally defined as an individual’s general HIV knowledge. It is important to acknowledge exploration was not included in the operational definition and therefore, not overtly assessed. Further, the operational definition cannot be considered a measure of the RPM construct of understanding and exploration and as such, cannot be considered relevant to a test of the theory. HIV-KQ-45 questionnaire addresses risk factors for acquiring HIV, transmission of HIV and general knowledge about HIV. Respondents could select one of the following answers: (a) true, (b) false or (c) don’t know. Questions answered correctly were given one point. Responses that were wrong or marked as “don’t know” were scored as incorrect and no point was awarded. A higher number/percentage of correct answers indicates greater HIV knowledge. The Cronbach’s alpha for this study was .83.

Normative data for the HIV-KQ-45 was collected with groups of college students and community members. Two groups of college students scored 85% and 82% correctly

and community members scored 74% correctly (Carey, Morrison-Beedy & Johnson, 1997).

The HIV Treatment Knowledge Scale (Balfour et al., 2007) assesses adherence, side effects and drug resistance. The questionnaire consists of 21 true or false questions. The Cronbach's alpha has been reported as .90 (Balfour et al., 2007). The greater number of correct responses indicates greater HIV treatment knowledge. The Cronbach's alpha for this study was .44. Reliability of individual questionnaire items was reviewed. Removing item number five would improve reliability to .51. Due to the low reliability, the HIV Treatment Knowledge Scale was not included in subsequent analysis.

### *Effectiveness*

Effectiveness was defined in two ways: directed attention and a source of rest or replenishment for directed attention and an individual's level of directed attention.

Digit span backward (Lezak, 1983) is a component of the Wechsler Adult Intelligence Scale (WAIS) and is considered the gold standard for assessing directed attention. This study used digit span backwards to measure directed attention. Digit span backward was administered verbally by the PI or RA to the women. Women were read a series of single, random digit numbers and asked to recite the numbers they heard backwards. Number series started with two numbers and ended with fourteen numbers. The numbers were read at a rate of one number per second. Random, single digit integers were generated from [www.randomnumbers.com](http://www.randomnumbers.com). All women were administered the same number sequences. Possible scores range from two to fourteen. Higher scores suggest greater directed attention. Normative data collected from healthy adults suggests



that the ability to recall five digits is the mean. The mean digit span backward score in this study was 4.49 with a range of scores from 2 to 8.

In this study, spirituality was considered an activity or intervention that restored directed attention in African American women. Spirituality was assessed using the Spiritual Well Being Scale (SWB) (Ellison, 1983). This scale has two subscales: Religious Well Being (RWB) and Existential Well Being (EWB). Each scale has 10 items for a total of 20 items. The scales are ranked from 1 (strongly agree) to 6 (strongly disagree). Scores range from 20 to 120. Cronbach's alpha for the Spiritual Well Being Scale for this study was .86. Normative data for the Spiritual Well-Being scale in HIV positive, African American men and women, had a mean score of 88.1( $SD = 18.69$ ) (Coleman & Holzemer, 1999).

#### *Meaningful Action*

Meaningful action was operationally defined as an individual's perceived fit and level of participation with other people, their community and environment. The operational definition of meaningful action lacked the component of feeling respected as outlined in the theoretical definition, as did the measures of meaningful action. Thus, similar to the understanding and exploration construct, the measures of meaningful action cannot be considered relevant measures to test the RPM. Meaningful action was measured using the Sense of Belonging Instrument (SOBI) (Haggerty & Patusky, 1995) and the General Mattering Scale (Rosenberg & McCullough, 1981). The SOBI is an 18 item instrument designed to capture the definition of sense of belonging. Sense of belonging is defined as, "the experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system

“(Hagerty et al., 1992, p.173). All 18 responses are in Likert scale format from 1 (strongly agree) through 4 (strongly disagree). Examples of items on the SOBI are “I feel left out of things” and “In general, I don’t feel a part of the mainstream society.” A lower score indicated less sense of belonging. The Cronbach’s alpha was .93 for this study.

The General Mattering Scale (Rosenberg & McCullough, 1981) is a five item questionnaire that asks respondents questions like, “How important are you to others?” and “How interested are others in what you have to say?” Responses are in Likert scale format from, “A lot” (associated with a numeric value of 1) to “Not at all” (associated with a numeric value of 4). Responses are reverse coded and higher scores indicate a greater sense of mattering. The Cronbach’s alpha for this study was .89. Data from homeless men revealed mean scores of 13.6 ( $SD = 3.5$ ). DeForge and Barclay (1997) interpreted mattering to others mean scores of 13.6 ( $SD = 3.5$ ) in a sample of homeless men as having high levels of mattering to others.

### **Depressive Symptoms, Drug and Alcohol Use and RPM**

#### *Depressive Symptoms*

Depressive symptoms was operationally defined as symptoms that typically correlate with clinical depression such as depressed mood, hopelessness, loss of appetite, sleep disturbance and feelings of worthlessness. Depressive symptoms were measured using the Center for Epidemiologic Studies Depression Scale (CES-D Scale) (Radloff, 1977).

The CES-D Scale is a 20 item questionnaire that questions feelings and thoughts from the proceeding 7 days. The questionnaire is based on a 4 point Likert scale 0 = rarely or none of the time (less than 1day), 1= some or a little of the time (1-2 days), 2 =

occasionally or a moderate amount of time (3-4 days) or 3= all of the time (5-7 days). Possible scores range from 0 to 60. Higher scores are more suggestive of depressive symptoms. The CES-D is a screening tool and not used to diagnosis clinical depression. The validity and reliability of the CES-D has been well established and Cronbach alphas are consistently reported greater than .80 (Radloff, 1977). The Cronbach's alpha of the CES-D in this study was .90.

#### *Screening for Alcohol/Drug use*

Brown et al. (2001) designed the two-item conjoint screening tool (TICS) to screen for alcohol and other drug problems that was used in this study. The questionnaire consists of the following two questions:

1. "In the last year, have you drunk or used drugs more than you meant to?"
2. "Have you felt you wanted or needed to cut down on your drinking or drug use in the last year?"

A positive response to one or both questions suggests a current substance abuse problem (Brown, et al., 2001). The Cronbach's alpha for the two-item conjoint screening tool was .81 in this study.

### **Sample Size Estimate and Data Analysis**

#### *Sample Size Calculations and Power Analysis*

Sample size for this study was calculated based on Cohen's (1992) seminal "Power Primer" article. The originally proposed eight explanatory variables for multiple linear regression (specific aim 2) required 107 participants for power of 0.80, medium effect size and alpha of 0.05. The omission of the HIV Treatment Knowledge Questionnaire resulted in seven explanatory variables for multiple linear regression which requires 102 participants for power 0.80, medium effect size and alpha of 0.05.

Since Specific Aim 1 focused on descriptive statistics, the proposed 110 subject sample size was adequate. Multiple linear and logistic regression models were the statistical analyses conducted in Specific Aim 2 Cohen (1992), 102 participants were necessary for a medium effect size with 0.80 power and 0.05 alpha (Cohen, 1992). Specific Aim 3 used linear regression models to test mediation. Thus, the 110 women who completed the survey were sufficient to achieve statistical power outlined in Aims 2 and 3.

#### *Data Analysis*

In order to maintain integrity of the data for analysis, the data were pre-coded and prepared for entry. Data was double entered into Excel and imported into SPSS (Version 14.0, SPSS Inc., Chicago, IL) to check for accuracy and cleaned. Cleaning the data was completed by reviewing the data and assessing Mahalanbois distance. Additionally, through SPSS capabilities, each single item from both imported data files were compared for similarity. SPSS noted discrepancies in an additional column. Discrepancies were reviewed, the raw data was re-examined and discrepancies were corrected. Assumptions of multiple linear regression including outlier cases were evaluated and transformations were considered. No transformations were made.

#### *Missing Data*

Missing data can result from respondent fatigue, refusal or participant error and are reported to be common in research (Polit, 1996; Tabachinck & Fidell, 2007). Missing data not exceeding 5% are acceptable according to Tabachinck & Fidell (2007). Missing data values in this study were assumed to be a result of participant error and random and did not exceed 5%. Thus, replacing the minimal missing data with mean

item scores was not appropriate given this type of study. Further, some of the questions were sensitive in nature. Only one woman did not answer either of the two sensitive questions asking about drug and alcohol use. The reasons this woman skipped these two questions are unknown.

Descriptive statistics and total number of responses for each measure are included in Table 3.1. The mean results for each measure are discussed in more detail in Chapter 4.

#### *Evaluation of Assumptions*

Regression assumptions of linearity, homoscedasticity, normality and univariate and multivariate outliers were evaluated using P-P plots, residual plots and Mahalanobis distance calculations for each outcome variable. Multicollinearity was examined by the tolerance and VIF values. VIF greater than 2.5 and tolerance of less than .40 were used as the criterion to indicate multicollinearity. All tolerance values were greater than .44 and VIF values were less than 2.4 for this study, which indicated that collinearity was not a problem.

With the use of a  $p < .001$  criterion of Mahalanobis distance (Tabachnick & Fidell, 2007), three outliers were found among all cases ( $N = 110$ ). The results were evaluated with and without the selected extreme cases. The extreme cases were double checked for data entry with response error. It was deemed that the extreme cases were based on missing data. Subsequently, two women were excluded from analyses including the HIV KQ because they had missed the entire first page of the questionnaire.

### **Specific Aim Testing**

#### *Specific Aim 1 Analyses*

Specific Aim 1: Explore the internal models of HIV illness in African American women living with HIV.

The 3CM cognitive map technique was used to assess the women's perceptions of their HIV/AIDS illness. The 3CM cognitive map technique is a measure of what one thinks about a related topic (Kearney & Kaplan, 1997). Words and phrases were assessed by counting the frequency in which women circled the word or phrase and the positive (+) or negative (-) affect she placed next to the word.

Words, phrases and sentences women hand scribed were evaluated by the PI and grouped into themes based on similarity and frequency of response. Most of the provided words and phrases in the exercise could be classified into two groups: (1) individual circumstance and (2) relationship type. The hand scribed phrases and words were examined for these characteristics. Most of the women who chose to free write used words that had been provided. Frequencies of circled words with a positive and negative sign were tabulated.

*Specific Aim 2 Analyses*

Specific Aim 2: Examine whether meaningful action, HIV knowledge and effectiveness predict adherence to medication taking behavior in African American women living with HIV.

Multiple linear regression analyses were used to examine the relationship among the variables; meaningful action, HIV knowledge, effectiveness, and depressive symptoms and drug and alcohol use and the continuous outcome variable of interest: self reported adherence. Multiple linear regression models were utilized to determine if meaningful action, understanding and exploration, effectiveness, depressive symptoms

and drug and alcohol use are predictive of adherence. The dependent variable of interest, adherence, was also transformed into a dichotomous variable and logistic regression analyses were also used to examine the relationships between meaningful action, understanding and exploration, effectiveness, depressive symptoms and drug and alcohol use on the dichotomous dependent variable of self reported adherence.

Specific Aim 3: Examine if depressive symptoms mediate the relationship between meaningful action and adherence and if meaningful action mediates the relationship between drug and alcohol use and adherence.

To explore the mediating effects of depressive symptoms and drug and alcohol use on adherence, techniques to test mediation as presented by Baron and Kenny (1986) and Judd and Kenny (1981) were used. Regression analysis between pairs of these variables was performed. First, drug and alcohol use and the two measures of meaningful action were regressed on the continuous and dichotomous dependent adherence variable. Second, depressive symptoms and the two measures of meaningful action were regressed on the continuous and dichotomous dependent adherence variable. Lastly, the interaction of the mediating and other variable was created and the remaining model variables were added to the regression models. Pearson's product- moment correlation coefficient was used to assess interactions.

## CHAPTER 4

### RESULTS

In this chapter, results of the study will be presented. Descriptive statistics of the women and model measures will be described, followed by the results of each specific aim.

#### **Descriptive Analyses of Model Variables**

A summary of the descriptive analyses of the measures used to assess the Reasonable Person Model concepts<sup>1</sup> and depressive symptoms and drug and alcohol are presented in Table 3.1.

##### *Adherence Measure*

The total score for the measure of adherence ranged from 0-100 with a mean of 79.40 ( $SD = 27.70$ ). Overall, women had high levels of reported adherence.

##### *RPM Measures*

###### *HIV Knowledge*

Understanding and knowledge was assessed by 3CM, the HIV Knowledge Questionnaire (HIV-KQ-45) (Carey et al., 1997) and the HIV Treatment Knowledge Scale (Balfour et al., 2007). The HIV-KQ-45 has a range of possible scores of 0- 45. The range of scores for this study was 16-44 with a mean score was 35.45 ( $SD = 4.99$ ). The mean score of 35.45 equates to a 78% correct. Overall, women had average HIV Knowledge.

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### *Effectiveness*

The effectiveness variable had two measures, one for each concept. Directed attention was measured by digit span backwards and restoration for directed attention was measured by the Spiritual Well-Being Scale. The range of scores for digit span backwards were 0-14. In this study, the range of digit span backwards scores was 2-8. The mean score was 4.49 ( $SD = 1.23$ ) which is slightly lower than a mean score of 5, which is considered normal (Lezak, 1995).

The Spiritual Well-Being scale has possible score ranges from 20-120. The ranges of scores for this study were 57-120 with a mean score of 89.11 ( $SD = 16.71$ ). Women had levels of spiritual well being consistent with other African American men and women living HIV.

### *Meaningful Action*

Meaningful action was measured by the Sense of Belonging Scale and the Mattering to Others Scale. The Sense of Belonging Scale had possible and observed range of scores between 18-72 with a mean score of 53.33 ( $SD = 11.38$ ). The Mattering to Others Scale has a possible range of scores between 5 -20. The observed range of scores was 6-20 with a mean of 17.24 ( $SD = 3.43$ ). Women in this study had a high mean score. Thus, they had high levels of mattering to others.

### *Depressive Symptoms*

Approximately 66% ( $n= 73$ ) of women had a CES-D score of 16 or greater indicating that depressive symptoms were present. The mean depressive symptoms score was 22.98 ( $SD = 12.58$ ). The possible range of depressive symptoms score was 0-60 and the observed range was 0-49. Approximately 50% of women ( $n=54$ ) had a score greater

than 23 indicating probable depression. The majority of women, 72%, reported having been diagnosed with depression, however, only 64% were receiving antidepressant medications. There were no differences in adherence between women who had been diagnosed with and treated for depression compared to women who had not been diagnosed or treated ( $\chi^2(2, N = 104) = 0.156, p = >.05$ ).

#### *Drug and Alcohol Screening*

Only 8% (n=16) women answered yes to one of the drug and alcohol use questions and 13% (n=26) answered yes to both questions. A “yes” response to one or two of the questions suggests a drug or alcohol problem. Thus, 36 women had a suspected problem with drug and/or alcohol use.

#### **Relationships Among Variables**

The measures selected to assess each concept were guided by the RPM but selected to increase the understanding of the lives of African American women living with HIV. The statistical analyses results of the exploration of the relationships among variable is not a test of the relationships of the RPM concepts since the measures selected were approximations of RPM concepts in the lives of African American women living with HIV.

Sense of belonging and mattering to others were strongly positively correlated with spiritual well being. Mattering to others and sense of belonging were strongly negatively correlated with depressive symptoms. Depressive symptoms and spiritual well-being were strongly negatively correlated. These findings suggest that women who had higher levels of mattering to others and sense of belonging had higher levels of spiritual well being and lower depressive symptoms scores. Additionally, HIV

knowledge scores were strongly positively correlated with adherence scores. Thus, women with higher HIV Knowledge scores had higher adherence scores (see Table 4.1 for all correlation values).

Table 4.1

*Correlations Among RPM Variables (N=108)*

Measure	Digit Span	CESD	Mattering to Others	Sense of Belonging	Spiritual Well Being	HKQ	Adherence
Digit Span	—						
CESD	-.184	—					
Mattering to Others	.064	-.606**	—				
Sense of Belonging	.106	-.694**	.567**	—			
Spiritual Well Being	-.014	-.414**	.329**	.466**	—		
HKQ	-.005	-.030	-.044	.181	-.038	—	
Adherence	-.114	-.217*	.124	.177	.055	.200*	—

\*\*two tailed  $p < .01$

\*two tailed  $p < .05$

### Results by Specific Aim

*Specific Aim 1.* Explore the internal models of HIV illness in African American women living with HIV.

The 3CM technique was used to explore the internal models of HIV/AIDS illness. Frequencies of words/phrases and the associated affect were tabulated and reported in Table 4.2.

Table 4.2

*Frequencies of 3CM Exercise*

Word	Circled and no sign	Circled with a negative sign	Circled with a positive sign	Not circled
Second Chance	15	9	53	33
Death Sentence	11	61	5	33
Sex	19	35	28	28
Taking Medication	16	14	62	18
Not Skipping Doses	16	18	51	25
Drug Resistance	12	30	26	42
Sick	15	47	17	31
Tired	11	42	22	35
Stress	14	53	18	25
Support	16	10	60	24
Fear	15	41	26	28
God	15	2	73	20
Church/Worship	11	5	63	31
Healthcare Provider	17	3	71	19
Stigma	7	44	12	47
Isolated	9	51	14	36
Depressed/sad	12	56	12	39
Healthy	8	12	57	33
Positive Attitude	11	6	68	25
Taking Care of Self	16	5	73	16
Children	9	7	65	29
Friends/family	12	8	66	24

Of the words provided in the 3CM exercise, the words most commonly circled with a positive sign were: God (68%), taking care of self (68%), healthcare provider (67%), positive attitude (63%), family/friends (61%), children (60%), church/worship (58%), taking medication (57%), support (55%) and healthy (53%). Women had strong positive feelings about support, God, church/worship, having a positive attitude, taking care of themselves, their healthcare provider and taking medications. Since this study was exploring medication taking behavior, “not skipping doses” and “drug resistance” were

added to the list. Few women circled the phrases drug resistance (39%) and not skipping doses (23%). The most common words circled with a negative sign were: death sentence (56%), depressed/sad (52%), stress (49%), isolated (47%). The tabulated frequencies were consistent with some of the free text women added.

Some women chose to write how they felt about words/phrases or living with HIV. The free text was examined for key words and affect and common themes emerged. Most free text words and phrases were categorized under individual circumstance or relationships. The common themes were similar to the frequency tabulations. Several women wrote about supporting relationships including: their children, friends, family and God being their support and very important to them. One woman wrote:

Living with HIV is not a death sentence. To live with HIV is not easy it is just that you have to have faith think positive and enjoy your life. With medications, discipline, self esteem and a support group filled with people you love and respect your life can be great.

Another woman wrote:

It's really hard to describe the feeling of being a AA woman with HIV/AIDS. Support medication and God has helped me the last 9 years and is extremely important. It's not a death sentence just mentally feels like one not physically. You can live long healthy life with positive attitude.

In the 3CM exercise, women more commonly circled relationship associated words and phrases and taking medication and associated these with positive affect and less frequently circled individual circumstances like stress, isolated, sick, tired and fear. Both free writing examples denounce HIV being a death sentence and mention the importance of having support. The phrase "taking medication" was more frequently circled with a positive association than were the drug resistance and skipping doses phrases.

*Specific Aim 2.* Examine whether meaningful action, HIV knowledge and effectiveness predict adherence to medication taking behavior in African American women living with HIV.

Multiple and logistic regression analyses were performed to examine the variables of meaningful action, HIV knowledge and effectiveness on adherence. The high levels of self-reported adherence resulted in limited variability in the adherence variable. Because of the limited variability in the dependent variable, the adherence variable was changed from a continuous variable into a dichotomous variable. The dichotomous splits were: 0-99 and 100 as recommended by Reynolds (personal communication, July 6, 2010); 0-59 and 60-100 (based on bimodal distribution of adherence scores); 0-92 and 93-100 (based on median adherence score) and lastly, 0-96 and 97-100 (natural cut off to double the number of persons included in the better adherence group compared to the 0-99 and 100 dichotomous split).

The multiple linear regression model for adherence included five predictor variables: HIV knowledge, digit span backwards, spirituality, mattering to others and sense of belonging. None of the five predictors was statistically significant. When depressive symptoms were added to the model, the model was still not significant (see Table 4.3).

Table 4.3

*Multiple Linear Regression Analysis of Reasonable Person Model Predicting Adherence*

(N=105)

Measures	b	SE b	$\beta$	<i>p value</i>
Reasonable Person Model				
Constant	78.457	37.606		
HIV Knowledge	1.051	2.149	.189	.060
Sense of Belonging	.002	.361	.002	.996
Mattering to Others	-.008	1.020	-.007	.994
Spirituality	-.080	.186	-.048	.666
Digit Span Backwards	-3.563	2.149	-.162	.100
Depressive Symptoms	-.573	.319	-.261	.075

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Full Model  $F(6, 105) = 2.027, p = .069$ ; Adjusted  $R^2$  for Adherence = .06

The logistic regression model for adherence dichotomized at 0-99 and 100 included six predictor variables: HIV knowledge, digit span backwards, spiritual well-being, mattering to others, sense of belonging and depressive symptoms. The Cox & Snell was .169 and Nagelkerke R Square was .267. (see Table 4.3) The full model was significant (omnibus test  $\chi^2(6, N=105) = 19.412, p = .004$ ). The logistic regression model had three of six predictors that did not include 1 at the 95% confidence interval. These predictors were: digit span backwards, mattering to others and depressive symptoms. Digit span was the most predictive variable. For every one unit increase in digit span backwards, the odds of having complete adherence decreased by nearly 50%, all else equal. Thus, having higher digit span backward scores which suggest greater working memory, decreased the odds of having complete adherence. Similarly, in relation to mattering to others, the odds of having complete adherence decreases by nearly 23% for every one unit increase in

matter to others, all else equal. Therefore, having a greater sense of mattering to others decreases the odds of having complete adherence. Lastly, for every one unit increase in CES-D, the odds of having perfect adherence decreases by 8.3%, all else equal. The goodness of fit test for the logistic regression model adequately fits the data (Hosmer and Lemeshow Test  $\chi^2$ , 9.330,  $p = .004$ ). Sense of belonging, spirituality, and HIV knowledge were not significant predictors ( $p > .05$ ).

Table 4.4

*Logistic Regression Analysis to predict adherence dichotomized as 0-99% vs. total Adherence (N=105)*

Measures				
Reasonable Person Model	$\beta$ (SE)	OR	<i>p</i> value	95% CI
Constant	9.669 (4.357)	15824.7	.026	
HIV Knowledge	-.068 (.056)	.934	.228	.837-1.043
Sense of Belonging	-.024 (.108)	.977	.524	.908-1.050
<b>Mattering to Others</b>	<b>-.259 (.108)</b>	<b>.772</b>	<b>.017</b>	<b>.624-.954</b>
Spiritual Well Being	.020 (.020)	1.020	.312	.981-1.061
<b>Digit Span Backwards</b>	<b>-.690 (.262)</b>	<b>.501</b>	<b>.008</b>	<b>.300-.837</b>
<b>Depressive Symptoms</b>	<b>-.066 (.033)</b>	<b>.936</b>	<b>.043</b>	<b>.878-.998</b>
Full Model: $\chi^2$ (6, N=105) = 9.330, $p = .004$ ; Nagelkerke $R^2$ : .267 Cox & Snell $R^2$ : .169				

Other logistic regression models that were performed with the various dichotomous splits of adherence (0-59 and 60-100, 0-92 and 93-100, 0-96 and 97-100) and the same independent variables (HIV knowledge, sense of belonging, mattering to other, spiritual well being, digit span backward and depressive symptoms) yielded non-significant results ( $p > .05$ ).



*Specific Aim 3.* Examine if depressive symptoms mediates the relationship between meaningful action and adherence and if meaningful action mediates the relationship between drug and alcohol use and adherence.

Mattering to others, sense of belonging and drug and alcohol use were separately regressed on the continuous and logistic variable of adherence. None of the predictor variables had a significant relationship with the adherence. Therefore, mediation was not performed because the first assumption per Baron and Kenny (1986) and Judd and Kenny (1981) was not met. Only 8% (n=16) of participating women answered yes to one of the drug and alcohol use questions and 13% (n=26) of participating answered yes to both questions. This means only 36 women, had a positive screening for possibly having a problem with drugs and/or alcohol is this study.

## **CHAPTER 5**

### **DISCUSSION**

The purpose of this study was to describe African American women's internal models of living with HIV and examine predictors of medication taking behavior. The modified Reasonable Person Model provided the framework for this study. The following sections provide a discussion of the results according to the specific aims, strengths and limitations, including recommendations for future research. Finally, implications for practice will be discussed.

#### **Exploring the Internal Models of HIV in Women Living With HIV**

Results from the 3CM exercise were consistent with findings from other studies (Edwards, 2006; Gant & Welch, 2004, Ironson & Kremer, 2009; Kremer et al., 2009; Knokle-Parker et al., 2008; Tufts et al., 2010) which concluded women report having support, faith and their relationship with God as facilitators to their adherence. Women in this study had strong positive feelings about support, God, church/worship, children, having a positive attitude, taking care of themselves and their healthcare provider. The "taking medications" phrase was also frequently circled and associated with positive affect. "Drug resistance" and "not skipping doses" were not as frequently cited showing them to be less important in the lives of women living with HIV. One could conclude from these results that these women did not have concerns with their ability to take medications as prescribed and that they perceived having support, friends, family, children, their healthcare provider and God as positive aspects of their lives living with

HIV. Only 14 women circled “taking medication” and associated this phrase with a negative sign. The results from the 3CM exercise may partially explain the high self-reported adherence scores and the limited variability in adherence.

### **Predicting Adherence**

In multiple linear regression models, none of the variables were statistically significant in predicting adherence and the model was not significant. Several logistic regression models were conducted and the only model which reached significance was based on dichotomizing adherence in terms of total or less than total adherence. Of the study variables, effectiveness (measured by digit span backwards), meaningful action (measured by mattering to others) and depressive symptoms were all statistically significant, negative predictors. For the digit span backwards and mattering to others variables, the prediction of decreased odds of having perfect adherence was an unexpected finding.

#### *Effectiveness (Working Memory)*

Increases in digit span backwards scores decreased the odds of having complete adherence in this study. Women with higher digit span backwards scores were less likely to have complete adherence. Digit span backwards is a measure of working memory. Clinicians and researchers alike have suspected that even the most minute, subclinical neurocognitive delays related to HIV may impair people’s ability to take medication as prescribed. Therefore, these results are unexpected. One possible explanation is Simpson’s Paradox, which means that there was a confounding variable not accounted for in this study like: an appropriate measure of restoration, the concept of exploration,

the length of time women had been taking medications or the dosing schedules of medications or social desirability.

Another possible explanation for this finding is that taking medication as prescribed is taxing and does wear down levels of directed attention. Thus, women who do take their medication as prescribed may have lower levels of directed attention because of taking their medication as prescribed. Alternatively, women who have higher levels of directed attention were perhaps able to more accurately recall their adherence over the past week and three months. Therefore, the usually “over-estimated” self-reported adherence was more accurately reported by women with higher directed attention scores as compared to women with lower levels of directed attention. Perhaps it was easier for women with lower levels of directed attention to report perfect adherence than thinking about times they have missed doses.

#### *Meaningful Action (Mattering to Others)*

Another unexpected finding was increased mattering to others scores decreased the likelihood of having perfect adherence. The mattering to others scale was selected as a measure of meaningful action because it was believed that the questions addressed feelings of belonging and being respected by others; which are concepts central to meaningful action. Meaningful action implies being respected by others and doing things that one knows others value. However, it is possible that the mattering to others scale was assessing the women’s sense of responsibility to others. The mattering to others scale includes the following questions: “How important are you to others?”, “How much would you be missed if you went away?”, and “How much do other people depend on you?” Given these questions, one possible explanation for this finding is that women who

reported higher levels of mattering to others may have significant friends, family or childcare responsibilities. These responsibilities may interfere with their ability to maintain high levels of adherence. For instance, women who have an HIV positive partner have reported lower levels of adherence because they are too busy worrying about the health and status of their positive partner (Edwards, 2006). Another example is childcare burden associated with non-adherence (Merenstein et al., 2009). It is likely that women who have childcare and other friends/family responsibilities that border a burdensome level, would score high on the mattering to others scale.

### *Depressive Symptoms*

In this study, most women had been diagnosed with depression but only approximately half of these women were currently taking medication for depression. Despite receiving treatment for depression, several women still scored 16 or greater on the CES-D. Women who had higher depressive symptoms were more likely to have less than complete adherence. The findings in this study were consistent with previously published literature that has concluded depressive symptoms negatively impact adherence (Anastos et al., 2005; Ahdieh-Grant et al., 2005; Cook et al., 2002; Kanek et al., 2010).

It is important to acknowledge only one of the four logistic regression models was statically significance. Therefore, these results should interpreted with caution. These predictors were not significant when the adherence variable was dichotomized at the following cut offs: 0-59 and 60-100, 0-92 and 93-100, and 0-96 and 97-100.

### **Mediation Effects of Depressive Symptoms and Meaningful Action**

There was an apriori concern that factors known to influence adherence, depressive symptoms and drug and alcohol use, would interact with the meaningful action concept. Therefore, this study was designed to examine if depressive symptoms mediates the relationship between meaningful action and adherence and if meaningful action mediates the relationship between drug and alcohol use and adherence. Mediation analyses to test these hypotheses were not performed because basic assumptions of mediation were not met.

### **Correlations Among Concepts**

Examining the relationships among concepts in this study is important because it is the first study conducted using the RPM to assess adherence. The sense of belonging, mattering to others and spiritual well being scores were significantly and negatively correlated with depressive symptoms. Women who have greater sense of belonging, mattering to others and spiritual well being are likely to have fewer depressive symptoms. Depressive symptoms is a known predictor of non-adherent medication taking behavior (Anastos et al., 2005; Ahdieh-Grant et al., 2005; Cook et al., 2002; Kanek et al., 2010). Further, HIV knowledge scores were significantly, positively correlated with adherence scores. While this significance was not seen in the full model, this correlation provides some evidence for the importance of HIV knowledge in assessing and predicting adherence and is consistent with other literature establishing the relationship between greater HIV knowledge and greater adherence (Weiss et al., 2003). This finding also lends support for the theoretical underpinnings of the RPM in an HIV adherence context; when people's informational needs are met (greater understanding of HIV) they are more

likely to act in a reasonable manner (take their medications as prescribed). Recall an excerpt from Kaplan and Kaplan (2006), “bringing out the best in people is more likely when their environments support exploration and understanding...” (p. 3). This study did not examine the exploration concept. However, the later described clinic setting where this study was conducted serves as an exemplar environment that likely supports exploration.

### **Summary**

Findings from this study are significant for several reasons. This is one of the few studies to use a theoretical framework to assess the antecedents to medication taking behavior in African American women living with HIV. Further, this is the first study to attempt selecting measures as an approximation of the Reasonable Person Model concepts to assess medication taking behavior.

In this study, working memory was the strongest predictor of less than perfect adherence, followed by mattering to others and depressive symptoms. Results of logistic regression models provided greater variance than multiple linear regression models. To the author’s knowledge, this is the first study to demonstrate African American living with HIV have less than average working memory capacity and working memory to be a predictor of medication taking behavior. Despite the counter intuitive relationship between working memory and adherence, clinicians may consider including assessments of working memory in clinical practice. Results from this study demonstrated that relationships exist between mattering to others, sense of belonging, spiritual well being and depressive symptoms. Assessing for and intervening with respect to depressive symptoms in African American women living with HIV could have positive impact on

their ability to maintain higher levels of adherence. This study also demonstrated that African American women were reporting depressive symptoms but of those reporting, few had been diagnosed with depression or were being treated for depression. Thus, clinicians should be encouraged to consider depressive symptoms as part of their adherence assessment in clinical practice.

Results from this study did not demonstrate a relationship between spiritual well being and working memory as originally hypothesized. It is possible that spiritual well being was not the correct measure of a type of restorative activity for directed attention. Perhaps assessing church/synagogue attendance would be a more appropriate measure in future studies. Further and in keeping more aligned with the theoretical framework, perhaps assessing women's contact and exposure to natural environments would have been more appropriate.

Despite the RPM predicting little variance overall, the aforementioned unexpected findings and relationships are thought provoking and provide foundations and insight for measuring the RPM concepts in future adherence research. Because the measures selected were not congruent with RPM concepts, these results should not be interpreted as a test of the theory, but, as a caution that selecting measures that are better estimates of the theory rather than conceptualizations based on the adherence literature, would likely yield different and more interpretable results. Selecting more appropriate and accurate measures for the RPM concepts may result in improved predictive value of the RPM.

### **Strengths and Limitations**

This study had several strengths. Most studies exploring medication taking behavior in African American women living with HIV have lacked a theoretical



framework. Additionally, there have been few quantitative studies conducted exploring adherence in African American women living with HIV. This study incorporated a theoretical framework that could be useful, if different measures were utilized, to assess medication taking behavior in future research.

Another strength of this study was that the exploring of the relationships between the concepts of the Reasonable Person Model in the lives of African American women living with HIV. Findings will add to the existing body of literature and factors that influence adherence in African American women living with HIV. The relationships between directed attention, mattering to others and adherence were unexpected and warrant further investigation. This study provided some insight to the types of appropriate measurement for RPM concepts. Spiritual well being was not the best measure of a restorative activity for directed attention. Measuring well-established environments and activities of restoration (e.g. natural environments) would have been more useful. Similarly, the measure of meaningful action lacked a central component; respect. Including the concept of respect, especially the woman's sense of respect by their provider, would have strengthened the measures of the meaningful action concept in this study.

There are several limitations to this study. This was a cross-sectional study and causal implications cannot be implied. The findings have limited generalizability because it was conducted with a specific population, African American women living with HIV in urban Minnesota. Women participating in this study were highly adherent. Women attending clinic regularly and support groups where this study was advertised are likely more adherent than women not in care and not accessing outside resources for

persons living with HIV. Adherence was only measured by self report. Virologic markers of adherence, HIV RNA, were not measured. Self reported adherence has a tendency of being over reported (meaning women report higher adherence than their actual adherence) and in this study, there was little variability in adherence scores. The high ceiling of adherence created an underpowered study and made it difficult to assess the study variables ability to predict adherence. Perhaps the women in this study are unique in their ability to maintain high levels of adherence or self-reported adherence was over estimated. It is possible these women did have the high levels of adherence they reported given most women were recruited from clinic visits. Had women who were not regularly attending clinic appointments participated in the study, perhaps the mean adherence score would have been lower. Monitoring clinic appointment attendance in junction with self-reported adherence and virologic HIV RNA would also be a recommendation for future measures of adherence.

Utilizing a theoretical model is a strength, but also a limitation. It is possible that there are better measures to assess RPM concepts. A limitation of this study was that the exploration concept was not included. The notion of feeling respected was not central to the measures used to assess the meaningful action concept. Future research utilizing the RPM should incorporate the concept of exploration in a more overt manner and use measures of meaningful action that include the concept of feeling respected.

It is important to acknowledge variables that likely influence women's adherence that were not assessed in this study. The clinic where this study was conducted provides HIV medication regardless of the patient's ability to pay for the medication. Rarely, are patients unable to obtain their HIV medications. The clinic provides patients' access to

case managers that can assist with housing, access to food, completing disability paperwork, and insurance applications. The clinic also provides appointments with pharmacists to meet with patients one on one to discuss medications, side effects, set up pill boxes and refill medications. Additionally, patients have access to a full time therapist and part time psychiatric clinical nurse specialist. Of the women who reported that they had been diagnosed with depression (n = 76), 64% (n=49) were taking depression medications. These important variables (having a case manager, meeting with a PharmD and/or therapist) were not assessed in this study and likely have a positive influence in the women's ability to be adherent to their HIV medications.

Given the low level of variance in the dependent variable of adherence and the low variance explained by the model in multiple linear regression results, the sample size was reevaluated utilizing, nQuery Advisor, a statistical software. According to nQuery Advisor, for a power of 80% at alpha .05, 6 covariates explaining 5.6% of the variance required 237 women for adequate power. According to nQuery, this study was underpowered. The 110 women that completed the study provided 41% power according to nQuery Advisor. Thus, the small sample size was a limitation in this study.

### **Recommendations for Future Research**

Conducting research that targets groups of African American women is useful in gaining understanding about medication taking behaviors and avenues for the development of interventions to improve adherence. Including study measures that are a closer conceptual fit to theoretical premise of the Reasonable Person Model is an important consideration for future research. In this study, spiritual well being was not a source of restoration for directed attention. However, it is possible that spirituality was

not assessed appropriately. The spiritual well being scale asked questions related to personal relationships with God and personal well being. Perhaps assessing the amount of time spent in a place or worship, the actual place of worship and/or praying or meditating would be a more appropriate measure of restoration. Further, examining known sources of restoration, like natural environments, could be more appropriate and useful for future research. Lastly, significant, positive, correlations were observed between spiritual well being and mattering to other and sense of belonging. It is possible that the spiritual well being measure was a closer approximation of the meaningful action concept than as source of restoration for directed attention.

The measurement of directed attention is a moving target. Having serial measurements of digit span backwards in conjunction with other measures of directed attention in longitudinal studies would provide a more robust measure of directed attention. Further, relying on one measure of adherence, that required directed attention, was not optimal.

The subjective patient report of adherence was obtained for this study. This study did not assess virologic measures of adherence. Having an objective measure of adherence like HIV RNA could provide a more accurate measurement of adherence than the sometimes over estimated, self report method. Having a more robust measure of directed attention and virologic measures of adherence over a longitudinal research design would provide a better data set to explore the relationships between directed attention and adherence.

As aforementioned, Simpson's Paradox could attribute to the unexpected results of greater directed attention predicting less than complete adherence. There are several

variables that could have influenced adherence that this study did not examine. The concept of social desirability is an important consideration for future research. Having matched virologic HIV RNA with self-report would tease out women who “over estimate” their adherence. Following up with women who tend to “over-estimate” their adherence may provide crucial insight into the concept of adherence. Perfect, 100% adherence is nearly impossible, exploring why women feel they need to report perfect adherence could be incorporated into future studies.

The clinical site in this study appears to be the “model” clinic by resources available to patients and likely realistic, high rates of adherence. This type of “model” clinic perhaps accounted for the unmeasured RPM concept of exploration. Women who attend this clinic have access to numerous resources that likely serve as an outlet for their “exploration.” This clinic provides assistance and referrals for other types of support (e.g. food, medical insurance, housing, bus fare, legal aid, etc.). Future research can continue to be conducted in this clinical setting but should include exploring the specific variables related to the clinic and providers like: access and appointments with case managers, therapy, support groups and pharmacists and relationships between patients and providers. Comparative studies could be conducted at different clinics providing HIV care services in Minnesota or other states.

This study was conducted by de-identifying the participant data. Future study designs could consider selecting out patients who report low levels of adherence and conducting face to face interviews to gain more insight to their medication taking behavior.

## **Implications for Practice**

Taking HIV medications as prescribed is vital to achieve optimal viral suppression and decrease morbidity and mortality. Providers should consider assessing a patient's depressive symptoms, especially when the patient is non-adherent. Ideally, depressive symptoms should be a component of readiness-to-start HIV medications given that results from this study have demonstrated that depressive symptoms are associated with less than perfect adherence.

It is likely that a woman's relationships and perceived support influence her ability to maintain adherence to HIV medications. However, this influence may be more appropriately viewed as a pendulum. If women have too many competing demands with friends and family, this may decrease her ability to maintain high levels of adherence. Conversely, if a woman has too little support, she may be less adherent to medications. Assessing and offering support through case managers, therapists and pharmacists could positively influence a woman's ability to maintain adherence and should be considered important wrap around services that HIV clinics may consider incorporating into the delivery of HIV care.

Adherence is multifaceted and complex behavior that changes over time. Providers need to be cognizant of and assess for barriers and facilitators to medication taking behavior during each client encounter because barriers and facilitators are fluid and dynamic.

## **Conclusions**

In this study, depressive symptoms decreased women's likelihood of having perfect adherence. Findings from this study suggest that depressive symptoms in African

American women living with HIV is under diagnosed, not effectively treated and interferes with women's ability to maintain perfect adherence. Screening for depressive symptoms should be incorporated into routine clinical care and assessments.

The purpose of this study was to examine relationships among HIV knowledge, directed attention, spiritual well being, mattering to others, sense of belonging, drug and alcohol use and depressive symptoms and adherence. This is one of the few studies to explore medication taking behavior from a theoretically posited framework, quantitative design, in African American women living with HIV. The RPM did not explain much variance of adherence or determine predictors of adherence. However, these findings should not be considered a test of the applicability of the theory to test these relationships given the measures may not have been congruent with the RPM constructs. Longitudinal study designs with more true to the theoretical underpinnings of the RPM would be novel and likely useful in determining predictors of adherence.

## APPENDIX

### *Items, Scales and Reliabilities of Empirical Measures*

<b>Concepts</b>	<b>Items</b>	<b>Type of Response</b>	<b><math>\alpha</math></b>
<i>Understanding and Exploration</i>			
HIV Knowledge Questionnaire	<ol style="list-style-type: none"> <li>1. HIV and AIDS are the same thing.</li> <li>2. There is a cure for AIDS.</li> <li>3. A person can get HIV from a toilet seat.</li> <li>4. Coughing and sneezing DO NOT spread HIV.</li> <li>5. HIV can be spread by mosquitoes.</li> <li>6. AIDS is the cause of HIV.</li> <li>7. A person can get HIV by sharing a glass of water with someone who has HIV.</li> <li>8. HIV is killed by bleach.</li> <li>9. It is possible to get HIV when a person gets a tattoo.</li> <li>10. A pregnant woman with HIV can give the virus to her unborn baby.</li> <li>11. Pulling out the penis before the man climaxes/cums keeps a woman from getting HIV during sex.</li> <li>12. A woman can get HIV if she has anal sex with a man.</li> <li>13. Showering; or washing one's genitals/private parts, after sex keeps a person from getting HIV.</li> </ol>	True, False, Don't Know	.83



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14. Eating healthy foods can keep a person from getting HIV.
  15. All pregnant women infected with HIV will have babies born with AIDS.
  16. Using a latex condom or rubber can lower a person's chance of getting HIV.
  17. A person with HIV can look and feel healthy.
  18. People who have been infected with HIV quickly show serious signs of being infected.
  19. A person can be infected with HIV for 5 years or more without getting AIDS.
  20. There is a vaccine that can stop adults from getting HIV.
  21. Some drugs have been made for the treatment of AIDS.
  22. Women are always tested for HIV during their pap smears.
  23. A person cannot get HIV by having oral sex, mouth-to – penis, with a man who has HIV.
  24. A person can get HIV even if she or he has sex with another person only one time.
  25. Using a lambskin condom or rubber is the best protection against HIV.
  26. People are likely to get HIV by deep kissing, putting their tongue in their partner's mouth, if their partner has HIV.
  27. A person can get HIV by giving blood.
  28. A woman cannot get HIV if
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- she has sex during her period.
29. You can usually tell if someone has HIV by looking at them.
  30. There is a female condom that can help decrease a woman's chance of getting HIV.
  31. A natural skin condom can help decrease a woman's chance of getting HIV.
  32. A person will NOT get HIV if she or he is taking antibiotics.
  33. Having sex with more than one partner can increase a person's chance of being infected with HIV.
  34. Taking a test for HIV one week after having sex will tell a person if she or he has HIV.
  35. A person can get HIV by sitting in a hot tub or a swimming pool with a person who has HIV.
  36. A person can get HIV through contact with saliva, tears, sweat or urine.
  37. A person can get HIV from a woman's vaginal secretions/wetness from her vagina.
  38. A person can get HIV if having oral sex, mouth on vagina, with a woman.
  39. If a person tests positive for HIV, then the test site will have to tell all of his or her partners.
  40. Using Vaseline or baby oil with condoms lowers the chance of getting HIV.
  41. Washing drug use equipment/ "work" with
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- cold water kills HIV.
  - 42. A woman can get HIV if she has vaginal sex with a man who has HIV.
  - 43. Athletes who share needles when using steroids can get HIV from needles.
  - 44. Douching after sex will keep a woman from getting HIV.
  - 45. Taking vitamins keeps a person from getting HIV.

HIV Treatment  
Knowledge  
Questionnaire

- 1. Once the HIV viral load results are ‘undetectable’, HIV medications should be stopped. True or False .49
  - 2. If HIV medications are not taken at the right time of day, HIV drug resistance can occur.
  - 3. HIV is cured with the HIV viral load blood test result is ‘undetectable.’
  - 4. Condoms during sex are not needed when the HIV viral load blood test results are at ‘undetectable’ levels.
  - 5. It is better to take a half dose of HIV medications than to stop the HIV combination medications completely.
  - 6. One can get infected with a drug resistant type of HIV.
  - 7. HIV medications can cause unpleasant side effects (e.g. nausea, diarrhea, vomiting).
  - 8. If sexual partners are both HIV positive condoms are no longer needed.
  - 9. Treatments are available to reduce HIV medication side effects.
  - 10. Recreational drugs (e.g. ecstasy) can affect the
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effectiveness of HIV medications.

11. Providing HIV medications to a pregnant woman reduces the baby's risk of being infected with HIV.
12. There currently exists an HIV vaccine that prevents HIV infection.
13. HIV medications can be taken at a different time of day on weekends or holidays.
14. Over-the-counter herbal pills (e.g. St. John's Wort) could make HIV medications less effective.
15. It is best to stop HIV medications as soon as you feel better.
16. Missing a few doses of HIV pills can increase the amount of HIV virus in the body.
17. After a few months, it becomes less important to take HIV medications at the right time of day.
18. HIV medications help the body's immune systems get stronger (CD4 increase).
19. When HIV medications work well, the HIV viral load increases.
20. Taking antibiotic medications protects a person from getting infected with HIV.
21. Physical exercise (e.g. yoga, tai chi) can help reduce stress levels in HIV patients.

*Meaningful Action*  
Sense of Belonging

1. I often wonder if there is any place on earth where I really fit in.

4pt Likert scale .93  
of Strongly  
Disagree to

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2. I am just not sure if I fit in with my friends. Strongly Agree
3. I would describe myself as a misfit in most social situations.
4. I generally feel that people accept me.
5. I feel like a piece of a jigsaw puzzle that doesn't fit into the puzzle.
6. I would like to make a difference to people or things around me, but I don't feel that what I have to offer is valued.
7. I feel like an outsider in most situations.
8. I am troubled by feeling like I have no place in this world.
9. I could disappear for days and it wouldn't matter to my family.
10. In general, I don't feel a part of the mainstream society.
11. I feel like I observe life rather than participate in it.
12. If I died tomorrow, very few people would come to my funeral.
13. I feel like a square peg trying to fit into a round hold.
14. I don't feel that there is any place where I would really fit in this world.
15. I am uncomfortable knowing that my background and experiences are so different from those who are usually around me.
16. I could not see or call my friends for days and it wouldn't matter to them.
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	17. I feel left out of things.		
	18. I am not valued by or important to my friends.		
Mattering to Others Scale	1. How important are you to others?	4pt Likert scale of Not At All to A Lot	.89
	2. How much do others pay attention to you?		
	3. How much would you be missed if you went away?		
	4. How interested are others in what you have to say?		
	5. How much do other people depend upon you?		
<i>Effectiveness</i> Spiritual Well-Being Scale	1. I don't find much satisfaction in private prayer with God.	6 pt Likert scale of Strongly Agree to Strongly Disagree	.86
	2. I don't know who I am, where I came from, or where I am going.		
	3. I believe that God loves me and cares about me.		
	4. I feel that life is a positive experience.		
	5. I believe that God is impersonal and not interested in my daily situations.		
	6. I feel unsettled about my future.		
	7. I have a personally meaningful relationship with God.		
	8. I feel very fulfilled and satisfied with life.		
	9. I don't get much personal strength and support from my God.		
	10. I feel a sense of well-being about the direction my life is headed in.		
	11. I believe that God is concerned about my problems.		
	12. I don't enjoy much about		

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	life.		
	13. I don't have a personally satisfying relationship with God.		
	14. I feel good about my future.		
	15. My relationship with God helps me not to feel lonely.		
	16. I feel that life is full of conflict and unhappiness.		
	17. I feel most fulfilled when I'm in close communion with God.		
	18. Life doesn't have much meaning.		
	19. My relation with God contributes to my sense of well-being.		
	20. I believe there is some real purpose for my life.		
Digit Span Backwards	1. Serial numbers read aloud. Participant to recite numbers heard, backwards.	na	na
<i>Depressive Symptoms</i>	1. I was bothered by things that usually don't bother me.	0-3 point scale, how often have you felt this way in the past week	.90
	2. I did not feel like eating; my appetite was poor.		
	3. I felt that I could not shake off the blues even with the help from family.		
	4. I felt that I was just as good as other people.		
	5. I had trouble keeping my mind on what I was doing.		
	6. I felt depressed.		
	7. I felt that everything I did was an effort.		
	8. I felt hopeful about the future.		
	9. I thought my life had been a failure.		
	10. I felt fearful.		
	11. My sleep was restless.		
	12. I was happy.		

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	13. I talked less than usual.		
	14. I felt lonely.		
	15. People were unfriendly.		
	16. I enjoyed life.		
	17. I had crying spells.		
	18. I felt sad.		
	19. I felt that people disliked me.		
	20. I could not “get going.”		
<i>Drug and Alcohol use</i>	1. In the last year, have you drunk or used drugs more than you meant to?	Yes or No	.81
	2. Have you felt you wanted or needed to cut down on your drinking or drug use in the last year?		
<i>Medication Taking Behavior Adherence</i>	1. How many doses did you miss yesterday?	Enter number of doses missed	
	2. How many doses did you miss the day before yesterday?		
	3. How many doses did you miss 3 days ago?	None to four	
	4. How many doses did you miss 4 days ago?	Never to all of the time	
	5. During the past 4 days, on how many days have you missed taking all your doses?	Yes or No	
	6. Most anti-HIV medications need to be taken on a schedule, such as “2 times a day” or “3 times a day” or “every 8 hours.” How closely did you follow your specific schedule over the last four day?	Never to all of the time Time frame, never to within the last 3 months	
	7. Do any of your anti-HIV medications have special instructions, such as “take with food” or “on an empty stomach” or “with plenty of fluids?”		
	8. If yes, how often did you		

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follow those special  
instructions over the last  
four days?

9. When was the last time you  
missed any of your  
medications?

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