PERSPECTIVES REGARDING ADHERENCE TO PRESCRIBED TREATMENT:
A FOCUS GROUP STUDY OF HIV POSITIVE MEN

DISSERTATION

Presented in Partial Fulfillment of the Requirements for
the Degree Doctor of Philosophy in the Graduate
School of The Ohio State University

By

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* * * * *

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ABSTRACT

A descriptive, cross-sectional research design, employing focus group methodology, was used to describe the medication adherence experiences of HIV positive gay men who self reported being adherent to their medication regimen. A high level of medication adherence is necessary for viral suppression and reduction in HIV-related morbidity and mortality.

The sample was comprised of 24 HIV positive gay men who were predominately Caucasian and ranged in age from 32 to 59 years. The majority of the participants had a household income greater than $50,000 and was living with a partner, roommate, or their children. Time since diagnosis with HIV averaged 10.1 years and the mean time between diagnosis and starting drug therapy was 2.25 years. The time on medications ranged from 9 months to 20 years. Twenty two (92%) of the men reported that their current viral load was undetectable.

A conceptualization of medication adherence as an evolving process comprised of three phases: initiation, incorporation, and maintenance, emerged from the data. Several themes were identified within each phase of the adherence process.
The initiation phases focused on the themes of “learning the diagnosis” and “initiation of medication”. The incorporation phase focused on the physical and emotional adjustments individuals made to incorporate HIV medications into their daily lives and move toward medication adherence. The themes associated with this phase were “struggles”, “side effects”, “stigma”, “motivators” and “being always adherent”. The maintenance phase focused on the ongoing behaviors and challenges identified with maintaining adherence behavior. The themes associated with the maintenance phase were “belief in medication”, “reminders”, “routines”, “significant others”, “healthcare provider relationship”, “acceptance”, and “positive attitude”. What can be taken from this study is that adherence is a complex and dynamic process rather than a static behavior. The process of becoming and remaining adherent is impacted by a myriad of unique factors.
Dedicated to my grandmother: Lorraine Dillen Sloan

“Nana”

Whose life was a lesson in love and kindness.
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I want to express my deep appreciation to the men who gave of their time and privacy to make this research possible.

And, finally, all of the people whose lives ended too soon because of HIV/AIDS and all of us whose lives are diminished by their passing. They are not forgotten.
VITA

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The appropriate and effective use of drug therapy is vital to a reduction of morbidity and mortality for individuals living with Human Immunodeficiency Virus (HIV) infection. A major development in the treatment of HIV infection was the introduction of Highly Active Anti-Retroviral Therapy (HAART) in the mid 1990s. The introduction of these medications led to improved treatment of HIV infections in the United States, dramatic reductions in death rates and significant improvements in clinical outcomes (Johnson et al., 2003; Karon, Fleming, Steketee & DeCook, 2001; Lewis & Abell, 2002; Murphy et al., 2001; Poppa et al., 2004; Thorner & Rosenberg, 2003; Reynolds, 2004; Vittinghoff et al., 1999; Zorilla et al., 2003). Prior to the advent of HAART, median survival after infection with HIV ranged from 8 to 12 years (CASCADE, 2003; Palella et al., 1998). A conceptual shift from the view of HIV infection as an acute and terminal illness to one more closely aligned with a chronic illness model has accompanied the decrease in HIV-related morbidity and mortality following the introduction of HAART (Heckman, 2003; Mitchell & Linsk, 2004; Nixon & Renwick, 2003; Shernoff, 2002).
While the clinical benefits of HAART are well documented these outcomes are not obtained without considerable difficulty in many cases. The most critical factor in achieving clinical success with HAART is the ability to maintain almost perfect levels of adherence to often challenging drug regimens (Arnsten et al., 2001; Arnsten et al., 2002; Bangsberg, Hecht, Charlebois, Chesney & Moss, 2001; Mostashari, Riley, Selwyn & Altice, 1998; Patterson et al., 2000). Given the near perfect levels of adherence needed it is not uncommon to find that sub-therapeutic levels of adherence are frequently exhibited by individuals on HAART (Bangsberg, et al, 2000; Chesney, Ickovics, Hecht, Skipia & Ragkin, 1999; Johnson et al., 2003; Patterson et al., 2000; Power et al., 2003; Reynolds et al., 2004; Wagner & Ryan, 2004). Less than optimal levels of adherence to HAART can potentiate the development of drug resistant strains of HIV that can increase morbidity and mortality for infected individuals and, if transmitted to others, pose a serious threat to public health (Hecht et al., 1998; Imrie, Beveridge, Genn, Vizzard & Cooper, 1997; Reynolds, 2004; Yerly, Kaiser, Race, Bru, Clavel & Perrin, 1999). A significant amount of research has been conducted to examine factors impacting individual adherence behavior.

Some studies have demonstrated no predictive relationship between socio-demographic factors and adherence behavior in general (Eldred, Wu, Chaisson & Moore, 1998). Several studies of HIV sero-positive individuals, however, have demonstrated positive correlations between certain socio-demographic factors and adherence. These factors include male gender, white race, older age, higher income, higher education and
Several additional factors shown to be predictive of adherence include a strong medical provider-patient relationship, improved t-counts, lower viral load and emotional (social) support from peers (Gonzalez et al., 2004; Lewis & Abell, 2002; Ickovics & Meade, 2002). Barriers to adherence found in these studies include forgetfulness, drug and alcohol use, drug side effects, problems taking medication at work, problems with refills, depression, and psychiatric illness. Numerous studies have examined variables in clients experiencing treatment failure or having difficulty maintaining adherence to their regimen (Deeks, 1998; Eldred et al., 1998; Frick, Gal, Lane & Sewell, 1998; Kennedy, 2002; Malow et al., 1998; Roberts, 2000; Samet et al., 2000). The majority of these studies have used heterogeneous samples as well as quantitative research methods.

A shift in adherence research focuses more on individuals who are HIV positive and report high levels of adherence to their treatment. Few studies have focused specifically on individuals who report high levels of adherence (Lewis, Colbert, Erland & Meyers, 2006; Malcom, Ng, Rosen & Stone, 2003).

**Purpose**

The purpose of this study was to explore the adherence of gay men who self report success adhering to HAART. By examining the adherence behaviors of gay men who report successful adherence it may be possible to discern commonalities among these individuals. Strategies seen as supporting successful adherence behavior might be shared with individuals currently having difficulty with medication adherence.
Research Objectives

The research objectives for the study were:

1. To describe the medication adherence experiences of HIV positive men who self-reported being adherent to their HAART regimen.
2. To describe what HIV positive men perceive facilitates successful medication adherence.
3. To describe what HIV positive men perceive as challenges to medication adherence.
CHAPTER 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

HAART consists of various combinations of drugs from three distinct drug categories: nucleoside analogues, non-nucleoside reverse transcriptase inhibitors (NNRTIs), and protease inhibitors (PIs). Each of these drugs works to interfere with a different step in the process of viral replication. The HAART protocol requires individuals to take a combination of these antiretroviral medications. In addition, individuals may need to take medications for prophylaxis and treatment of HIV-related infections (Ickovics & Meade, 2002).

During HIV replication viral nucleic acids (RNA) are copied, converted into DNA and linked with DNA of the host cell. During the course of normal HIV replication subtle changes in the genetic code of the virus often occur and result in genetic mutations. Most mutations are incompatible with viral existence and do not result in a new strain of virus. Some mutations do, however, result in changes in genetic sequencing compatible with viral existence. These changes can potentially allow for development of a new strain of HIV. Drug resistance can develop when these mutations occur in the presence of antiretroviral medications.
It is important that once antiretroviral therapy (HAART) has been initiated adherence is such that adequate serum drug levels are maintained to reduce viral replication, decreasing the chance for mutations, and reducing the likelihood that a drug resistant strain of HIV will develop (Ickovics & Meisler, 1997). Maintaining adequate serum drug levels requires that antiretroviral drugs be taken exactly as prescribed. There is very little margin for error in adherence to antiretroviral therapy, as it requires nearly perfect adherence for success (Lewis & Abell, 2002).

Non-adherence is not only of concern because of the potential negative impact on an individual, but also as a substantial risk to public health. Non-adherence by an individual client can result in the development of drug resistant virus. Currently HAART is based on a limited number of effective drug treatments within three drug classes. Resistance to one drug within a specific class can result in decreased efficacy of other drugs in that same class. For the individual this reduces treatment options that prevent HIV-related infections and death. As a public health concern, the development and transmission of drug-resistant strains of HIV has the potential of negating much of the progress made in the development of effective treatments. The potential proliferation of drug-resistant strains of HIV could have results similar to what was seen in the 1980s when effective treatments were unavailable for HIV and AIDS. The current outcome by which HAART is evaluated is an increase in CD4 cell counts, a reduction in plasma viral load (level) and clinical improvement in the patient. An undetectable viral plasma level is considered optimal and has been linked to clinical improvement. (Bangsberg et al, 2000; Friedland & Williams, 1999; Singh, et al, 1999).
Ickovics and Meade (2002) contend that adherence is critical to obtain the full benefits of HAART, including maximal and durable suppression of viral replication, reduced destruction of CD4 cells, prevention of viral resistance, promotion of immune reconstitution and slowed progression to AIDS. Both the difficulty and the importance of adherence with HIV medication are well documented. During HIV replication viral nucleic acids (RNA) are copied, converted into DNA and linked with DNA of the host cell. During the course of normal HIV replication subtle changes in the genetic code of the virus often occur and result in genetic mutations. Most mutations are incompatible with viral existence and do not result in a new strain of virus. Some mutations do result in changes in genetic sequencing compatible with viral existence. These changes can potentially allow for development of a new strain of virus. Drug resistance can develop if these mutations occur in the presence of anti-retroviral medications.

It is imperative that once antiretroviral therapy (HAART) has been initiated adherence is such that adequate serum drug levels are maintained to reduce viral replication, decreasing the chance for mutations, and reducing the likelihood that a drug resistant strain of HIV will develop (Ickovics & Meisler, 1997). Maintaining adequate serum drug levels requires that antiretroviral drugs be taken exactly as prescribed. There is very little margin for error in adherence to antiretroviral therapy, as it requires nearly perfect adherence for success (Lewis & Abell, 2002).

Non-adherence by the individual client can result in the development of drug resistant virus. Currently HAART is based on a limited number of effective drug treatments within three classes of drugs. Resistance to one drug within a specific class often results in decreased efficacy of other drugs in that same class. For the individual
this reduces treatment options that stand between HIV infection and death. On a public health scale, the development and transmission of drug-resistant strains of HIV has the potential of negating much of the progress made in the development of effective treatments. The proliferation of drug-resistant strains of HIV could have results similar to what was seen in the 1980s when no effective treatments were available for HIV and AIDS. The current outcome by which HAART is evaluated is a reduction in plasma viral load (level) and clinical improvement in the patient. An undetectable viral plasma level is considered optimal and has been linked to clinical improvement. (Bangsberg et al., 2000; Barlett, 2002; Chesney, 2003; Singh, et al, 1999).

Determinants of Adherence to HAART Model

Ickovic and Meade’s (2002) Determinants of Adherence to HAART Model was the framework used to guide the study. This model was adapted from Ickovic and Meisler’s (1997) Framework for clinical research and clinical trials. The framework consists of five separate concepts related to individual adherence to HIV medications (See Figure 2.1).
Figure 2.1. The Determinants of Adherence Model (Ickovics & Mead, 2002)
These concepts are patient characteristics, treatment characteristics, patient-provider relationship, clinical setting and disease characteristics. Ickovic and Meade’s model (2002) suggest that these factors influence each other and individually and collectively impact individual adherence. Patient characteristics include certain psychosocial and socio-demographic factors.

Among the psychosocial factors found to impact adherence behavior are active drug or alcohol use, concerns about weight or body image, psychiatric illness, self-efficacy, social support, positive state of mind (PSOM) defined as an individual’s capacity to enter positive cognitive and interpersonal states, and routinization of daily behaviors (Altice, Mostashari & Friedland, 2001; Andreo et al, 2001; Broers, Morabia & Hirschel, 1994; Chesney et al, 2000; Eldrded et al, 1998; Gonzalez, et al., 2004; Gordillo, del Amo, Soriano & Gonzalez-Lahoz, 1999; Horowitz, Adler & Kegeles, 1988; Kleeberger , et al. 2001; Morse et al, 1991; Roberts & Mann, 2000; Singh et al, 1996; Singh et al , 1999; Stein, Rich, Maksad, Chen & Hu, 2000; Tucker et al., 2004; Tuldra et al., 2000; Wagner & Ryan, 2004; Weidle et al., 1999). Chesney (2000) also demonstrated that the ability to identify medication and treatment regimen and an understanding of the relationship between adherence and drug resistance correlates with increased adherence.

Socio-demographic factors have generally been found to have little predictive value in relation to adherence behavior (Eldred et al, 1998; Wise, 1996). Several studies, however, have found that certain socio-demographic factors (higher income, literacy, male gender, older age, and white race) do correlate with higher levels of adherence (Chesney et al, 2000; Gifford, et al, 2000; Kleeberger et al, 2001).
A number of treatment-related characteristics have been found to have an impact on adherence behavior. Medication-related side-effects have been found to have a negative impact on adherence behavior (Altice et al, 2001; Gao et al, 2000; Roberts & Mann, 2000; Wall et al, 1995; Weidle et al, 1999). Adherence has been found to be impacted by the complexity of treatment (Altice et al, 2001; Eldred et al, 1998; Wall et al, 1995), the number, type and frequency of medication dosages (Cockburn, Gibbard, Reid & Sampson-Fisher, 1987; Freeman, Rodriguez, & French (1996); Goebel, 1995; Kleeberger et al, 2001; Samet et al, 1992), perceived fit of treatment into daily routine (Gifford et al, 2000), food restrictions, adverse events and complexity of schedule (Gallant & Block, 1998), and perceptions of HIV and HAART.

*Research related to high adherence*

There is little research that examines factors related to adherence in individuals who demonstrate high levels of adherence. Malcolm, Ng, Rosen and Stone (2003) compared subjects with excellent adherence (defined by the authors as taking medication consistently more than 90% of the time) to subjects with suboptimal adherence (defined as taking medication consistently less than 75% of the time). Their study, based on tenets of the Health Belief Model, used semi-structured interviews to examine attitudes and beliefs of forty-four HIV sero-positive individuals currently taking HAART. The results of their study are consistent with findings of previous research in the area of adherence and suggest beliefs about medication efficacy and the importance of adherence, patient-provider relationships, social support, active substance abuse and depression differ
between individuals with excellent adherence and those with sub-optimal adherence levels. A major shortcoming of the study was that it did not address strategies employed by those individuals with high levels of adherence to overcome identified barriers to excellent adherence.

Two other recent studies also used qualitative methodology to examine the experiences of individuals reporting high levels of HIV medication adherence. Gray (2006) used individual interviews in her grounded theory study of an ethnically diverse sample of 11 persons living with HIV. The purpose of her study was to understand the process of becoming adherent from the participant’s perspective. Lewis, Colbert, Erland & Meyers (2006) used semi-structured interviews to describe the adherence-related behaviors and attitudes of a sample of 13 mostly white, low income and unemployed men living with HIV.

Significance of the study

Much of the research to date in the area of adherence to HAART has focused on measurement and issues of non-compliance. The advent of HAART in the mid 1990’s provided hope in the treatment of HIV/AIDS. The dramatic reduction in morbidity and mortality associated with HAART was clear and convincing evidence that this new treatment regime had great value. Much research has been conducted within the context of the medical model and assumes that, due to the benefits, adherence to medication should be the primary and overarching goal for individuals with HIV regardless of the associated costs. Those who would not or could not adhere must be operating under the
negative influence of variables that, if identified, could be mitigated and result in successful adherence. Few studies have addressed the experiences of individuals on HAART for the purpose of understanding the meaning of that activity and the need to incorporate the demands of such medication into daily routines.

A large number of studies, mostly quantitative in nature, have attempted to identify variables that impact adherence, most often by examining those who are not successful. While these studies have had some limited success in identifying some barriers to adherence, such as depression or active substance abuse, they are far from definitive. Even fewer studies have delineated universal factors that enhance one’s ability to adhere to HAART. There is a scarcity of research approaching the question of medication adherence from the perspective of individuals who identify as successful for the purpose of describing how they incorporate the rigors of taking medication in their daily lives. This study sought to elucidate the meaning of taking medication for such individuals, to identify facilitators and challenges of adherence.
CHAPTER 3

METHODS

Research Design

A descriptive, cross-sectional research design was used to study HIV positive men who self reported successful adherence to their HAART regimen. Focus group methodology was used to obtain data for the research objectives. The Ohio State University Behavioral and Social Sciences Human Subjects Review Committee approved the research prospectus prior to initiating the study.

Research Objectives

The following three research objectives were addressed in this study.

1. To describe the medication adherence experiences of men who are HIV positive and self-report being adherent to their HAART regimen.

2. To describe what HIV positive men perceive facilitates successful medication adherence.

3. To describe what HIV positive men perceive as challenges to medication adherence.
Sample

The investigator anticipated recruiting a sample of 30 men who self-report being HIV positive. The inclusion criteria for being a participant in the study were: (1) HIV sero-positive, status known for at least 12 months, (2) currently employed, (3) 25 years of age or older, (4) currently taking anti-retroviral medications, (5) perceived (per self-report) being adherent to the HAART regimen, (6) speaks, reads, and understands English, and (7) agrees to be in the study.

Participants were recruited by word of mouth and printed fliers. The main sources for recruiting participants were fliers, word of mouth, church bulletins, and newsletters at the King Avenue United Methodist Church. Written consent was obtained from the church pastor to recruit potential participants and conduct the focus groups at the church.

Procedure

Potential participants learned about the study from fliers, word of mouth, information in the church bulletin, or in the newsletter of the church (See Appendix A). Printed recruitment materials included a basic description of the study, inclusion criterion and reimbursement information. In addition, information was included about how to contact the investigator, if interested in being in the study. Upon contacting the investigator, potential participants were screened with a basic question format to assure compliance with study inclusion criteria. An individual who met the study criteria was asked if would be willing to participate in a focus group interview lasting approximately two hours.

Contact information was obtained from the participant at that time. Willing and eligible participants were asked to participate in focus groups with no more than seven
other participants. Times and dates for focus groups were established by the investigator once an adequate number of participants were recruited for a group session.

All focus groups were conducted in a discrete and quiet room at the King Avenue United Methodist Church. This location was chosen as the church is welcoming of the gay community, but not overtly connected to any HIV/AIDS organization. The church was easily accessible from all part of the city, had adequate parking and private meeting rooms which were provided free of charge. All groups were conducted in the evening and on weeknights.

Informed consent was obtained when the participant arrived at the research session. Each participant was asked to give standard written consent verifying willingness to participate in the focus group. The Ohio State University Behavioral/Social Sciences Consent form was used. This consent attested to the informed and voluntary nature of their participation as well as their knowledge that the interviews would be audio taped and how the data would be used. Each participant was assured that he could terminate participation at any time. Prior to beginning the focus group, each participant was asked to complete a background information form.

Each focus group was conducted by the investigator and audio taped so it could later be transcribed for data analysis. Participants received $25 for participating in the study.

*Focus Group Methodology*

Focus group interviews were used as the primary strategy for data collection in this study. Focus group interviews are particularly useful in obtaining multiple perspectives about a topic in a concise manner while providing insight into the shared
understanding help by group participants (Gibbs, 1997). Attitudes, feelings and beliefs are more likely to be revealed through the group process unique to focus group methodology (McLafferty, 2004). Focus groups have been used by other investigators doing research with HIV/AIDS individuals (Nyamathi & Shuler, 1990; Reynolds, Neidig & Brashers, 1999; Reynolds, Neidig & Wewers, 2004).

Focus groups have been used as a research data collection method for over seventy years, however, there still exists a lack of agreement on a number of key issues for this methodology (Krueger & Casey, 2000). There is no clear standard as to the number of participants within a single focus group or the number of groups that should be conducted on a specific topic. The literature suggests that groups may acceptably range in size from four to twenty participants (Gibbs, 1997; Krueger & Casey, 2000; McLafferty, 2004). Krueger and Casey recommend that a group be no more than eight in research studies. They suggest using a smaller group if “the questions are meant to gain an understanding of people’s experiences and the researcher wants more in-depth insights” (p. 74).

In a review of literature McLafferty (2004) found that the suggested number of focus groups on a specific topic ranges from one to twelve and that when data becomes redundant an adequate number of groups has been achieved. Krueger and Casey (2000) recommend that three or four groups should be conducted and then a decision should be made as to whether a point of theoretical saturation (not gaining new insights) has been reached. Some authors suggest that the greater the variability of the participants in focus groups will require more groups to reach a point of saturation (Krueger & Casey, McLafferty). The maximum number of participants in each group for this study would be
no more than eight. In actuality none of the groups were larger than four participants. The researcher scheduled a focus group as soon as enough eligible participants were identified to conduct a group as the investigator did not want a potential participant to need to wait longer than two weeks to be in a focus group.

Based on what is suggested in the literature about conducting focus groups with homogenous participants, four individual focus groups were initially planned for the study. The investigator and his advisor determined even though there was evidence of data saturation that two more groups would be conducted to increase the sample size for study and make sure no new themes emerged. Each focus group lasted no longer than ninety minutes to allow adequate time for input from all participants.

Krueger and Casey (2000) suggest that five categories of questions be used in conducting the focus group interview: opening, introductory, transition, key and ending questions. Opening questions establish rapport and get interaction between group members. Questions should be easy to answer in a brief way and are not typically analyzed. Introductory questions are used to introduce the topic of discussion and get participants to begin thinking about the topic of interest using an open-ended approach. Transition questions serve as a bridge from the introductory to the key questions and serve to make a connection between the participant and the topic being investigated. Key questions serve as the main focus of the study. Finally, ending questions are used to bring a sense of closure to the interview and serve to reflect on and summarize what has occurred.
Focus Group Questions

The interview questions for the focus groups were developed from Ickovic and Meade’s (2002) Determinants of Adherence Model that guided the study. (See Appendix B). The questions were designed to focus discussion on the research objectives addressed in this study: 1) to describe the medication adherence experiences of men who are HIV positive and self-report being adherent to their HAART regimen, 2) to describe what HIV positive men perceive facilitates successful medication adherence, and 3) to identify what HIV positive men perceive as challenges to medication adherence.

The two key questions used were 1) What was it like for you to begin taking HIV medication? and 2) What is it like now to take medications? In addition, several probing questions were used that pertained to what has been helpful in being adherent, what has been problematic, role of significant individuals, and relationship with health care providers.

Background Information Form

The background information form was developed based on a review of adherence literature to identify areas that may impact an individual’s ability to adhere to a medication regimen. Also Ickovic and Meade’s (2002) model was used in deciding on what socio-demographic and health information should be included. The form has 24 questions. These questions were included to gather information about characteristics or behaviors of study participants used in describing the sample. (Appendix C).

Data Analysis

The data from the background information form were analyzed using descriptive statistics. Each focus group audio tape was transcribed by the investigator or an assistant.
The investigator reviewed the transcripts for accuracy and to capture the interactions within the group. The transcripts were analyzed to develop codes for data analysis. Categories of responses were coded using an emergent approach described by Haney, Russell, Guklek & Fierros (1998), which consists of several steps. First, using a single transcript, the investigator and his dissertation advisor conducted independent reviews of the transcript to condense responses into classifications to which a coding scheme could be applied. Second, they discussed their findings, established agreement between their initial coding schemes, and created a consolidated coding scheme. The coding schemes were based on the topics in the focus groups. Third, the consolidated coding scheme was used to independently code a second transcript. Fourth, the results of the independent coding of the second transcript were compared to determine the reliability of the coding. Two forms of reliability are desired: 1) stability or the same coder getting the same results each time, and 2) reproducibility (inter-rater reliability) or coding schemes that produce the same results from different people (Stemler, 2001). For inter-rater reliability a 95% agreement is suggested. Haney et al. (1998) suggest using a Cohen’s Kappa (which equals 1 if coding agreement is perfect) of .8 or greater to determine inter-rater reliability rather than a percentage (number of cases coded the same divided by the total number of cases coded) as there is a degree of agreement that will occur between raters due to chance which is not accounted for in the percentage approach. If an acceptable level of agreement is not achieved the independent coders repeat the process. Once agreement has been reached the coding scheme can be used with the remaining transcripts.
The investigator and his advisor discussed any differences between their coding of the two transcripts and were able to reach consensus on the coding. The same process was done with all six transcripts to reach consensus about the codes and the themes that emerged from the data. The code and themes were present in all six transcribed focus group data. The codes and themes were synthesized into the process that emerged regarding the participant’s experiences in being adherent to their HIV treatment (Krippendorf, 2004; Lofland & Lofland, 1995).
CHAPTER 4

FINDINGS

Chapter four includes the results and interpretation of the data from six focus groups conducted by the investigator between June and November 2006. All focus groups were held in a church welcoming of the gay community but not overtly connected to any HIV/AIDS organizations. Prior to granting permission for the study, the church pastor reviewed a description of the study and discussed the study with the investigator. The church was easily accessible from all parts of the city, had adequate parking and private meeting rooms which were provided free of charge. All groups were conducted in the evening on a weeknight and followed the procedures presented in Chapter three. This chapter provides a description of the sample, the findings and interpretation of the data from the focus groups, and discussion.

Description of the Sample

The sample consisted of 24 HIV positive men who perceived themselves as being adherent to their prescribed medication treatment. Each man participated in one of six focus groups with three other participants. Table 4.1 provides the demographic characteristics of the sample. All participants were HIV positive males who self-identified as gay, twenty-three were Caucasian and one was African-American.
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Table 4.1 Demographic characteristics of the sample (N = 24)
Ages ranged from 32 to 59 years with a mean age of 45.34 (S.D. = 7.54) years. Fifteen reported being single and nine being partnered. The nine partnered participants lived with their partner, three participants lived with one roommate and two lived with their children. The reported yearly self income and household income ranged from less than $25,000 to greater than $100,000. Eighteen (67%) of the participants reported personal incomes greater than $25,000 and two of these above $100,000. In terms of household income, 19 (79%) reported an income over $25,000 and 5 of these above $100,000.

In regard to alcohol use, six participants reported no alcohol use, while 11 (46%) reported drinking once or twice a week. None of the participants reported daily alcohol intake. Nineteen (79%) participants denied using illicit drugs, however 4 claimed to use them once or twice a year and one person reported monthly use. No one reported using illicit drugs on a weekly or daily basis. Drugs used by those who reported some illicit drug use included marijuana (2), ecstasy (Methylenedioxymethamphetamine) (3), K (ketamine) (2), and GHB (1).

Table 4.2 provides characteristics of the sample in regard to health history related to being HIV positive. Time since diagnosis with HIV ranged from 21 years (1985) to 1 year (2006) with a mean time of 10.1 (S.D. = 6.18) years. The amount of time between diagnosis and starting drug therapy ranged from 0 to 8 years with a mean of 2.25 (S.D. = 2.61) years. The number of years on medication ranged from nine months to over 20 years with a mean of 8.42 (S.D. = 5.47) years. Participants reported taking between two
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Table 4.2. Health characteristics of the sample (N=24)
and eleven pills per day for HIV or HIV-related conditions with an average of 6.17 (S.D. = 2.68) pills per day. The number of times each participant took pills per day ranged from one to five times with a mean of 2.75 (S.D =1.48) times. In regard to HIV-related health problems 15 (63%) participants reported having from one to seven. Some of these problems were opportunistic infections, full blown AIDS, wasting syndrome, peripheral neuropathy, diarrhea, and dermatological conditions. Eight (33%) participants reported having been hospitalized at some point for HIV-related problems. Twenty two (92%) participants reported currently having an undetectable viral load. Current CD4 counts ranged from 119 to 900 with an average of 530.64 (S.D. = 196.58). Participants identified their lowest CD4 counts ranging from zero to 600 with an average low of 196.63 (S.D. = 169.63). Self-reported adherence to HIV medication was 92% for the past three days, 96% for the past two days and 100% for the past 24 hour period.

Focus Group Findings

The data from all six focus groups were analyzed as described in the methods chapter. The concept of adherence as a process from diagnosis to present emerged from the analysis of the data. For most participants becoming adherent to a medication regime was described as a process. Some participants claimed to have been adherent from the start, however, all reported encountering struggles accepting their diagnosis, needing to be on routine medication and/or incorporating the regime and associated side effects into their lives. Over time the participants moved toward acceptance of their HIV status and the need to take medication. The medication requirements (doses, schedules) changed and became easier to integrate into daily routines. Most participants identified supportive
others who played a role in their transition to acceptance of their diagnosis and the need to be on medication for HIV. The relationship with their healthcare provider, (predominantly a physician), was identified as significant in the process of becoming maintaining adherence behavior. All participants in the study reported that adherence to their medications had become routine and almost all reported reaching an acceptance of HIV as being just another part of their life.

The findings are presented in terms of the three research objectives and the three phases that emerged during the analysis. These phases were initiation, incorporation, and maintenance. The first objective was to describe the medication adherence experiences of men who are HIV positive and self report being adherent to their HAART regime. The second objective was to describe what these men perceive facilitates successful medication adherence and the third objective to describe what they perceive as challenges to their medication adherence. The two key questions used in the focus groups were 1) what was it like for you to begin taking HIV medication?, and 2) what is it like now to take medications? In addition, several probing questions were used to ascertain what things had been helpful and problematic in becoming and remaining adherent, what role did other people play in the adherence process and qualities of the relationship with the health care provider.

Medication Adherence Experiences

The findings regarding the medication related experiences of currently adherent HIV positive gay men are organized in terms of the three phases that emerged from the data and represent an evolving process rather than a static state. These phases include
initiation, incorporation and maintenance. A number of themes emerged within each of these phases. Some of these themes are unique to one specific phase while others reoccur throughout the adherence process. Similarly, challenges and facilitators of adherence were identified. Some of these are unique to a specific phase while others reoccur throughout the adherence process.

**Initiation**

All participants identified some level of difficulty during the initial phase of the HIV medication adherence process. The initiation phase focused on events associated with learning of the HIV diagnosis and the decision to start HIV medication. The themes that emerged in this phase were learning the diagnosis and initiation of medications.

One thing that that all participants in this study shared in common is that the adherence process began at the same point, learning of the HIV diagnosis. While not all participants began taking medications for HIV at the time of diagnosis, it can be argued that awareness of one’s HIV positive status was a necessary starting point in the medication adherence process. For some participants, awareness of their HIV status and starting on medication were simultaneous events, often prompted by the presence of an HIV-related illness. For other participants, and for a variety of reasons, diagnosis and starting medications were events separated by some amount of time. For a majority of participants, the task most associated with this early phase was coming to terms with the HIV diagnosis and the need to be on medication.
Learning the Diagnosis

Many participants were diagnosed with HIV in relation to a serious illness or a change in their physical health status. Some participants learned their diagnosis while hospitalized with an opportunistic infection, such as pneumonia, or another life-threatening condition. A few reported seeking an HIV test in relation to the illness or death of an intimate other.

_The reason I got tested in the first place was my partner at the time got pneumonia and was diagnosed with full blown AIDS._

There were a number of individuals, especially those diagnosed within the last ten years or so, who sought HIV testing in the absence of overt physical changes.

Almost all participants experienced some struggle accepting their HIV status and incorporating medications into their daily routine. The initial reaction to having HIV included a range of emotions such as depression, fear, anger, self-blame, and denial. For most the initial reaction included depression.

_I was very depressed...I focused too much on the future, which wasn’t good._

_I was a cry baby for weeks it seems I just couldn’t get it out. I cried all the time._

Others identified fear as one of their early reactions as they believed they would die quickly because of HIV.

_I thought I had about a month to live. My awareness of the disease was that it was a death sentence._

_I just thought it was a death warrant and I was going to be dead within the next 10 years. Physically it didn’t make me sick, but mentally it was a death warrant to me for quite a few years after that._
A very common reaction expressed by the participants was one of denial.

*I just forgot about it and, to be honest with you, I didn’t worry about it.*

*I went out and had fun with my friends and didn’t really talk about it.*

The initial process of coming to terms with the new status of being HIV positive often involved the assistance of a key figure who provided direction and support during the participant’s early struggles:

*I was sitting there eating at the bar and he must have thought there was something wrong with me cause he came up and asked me what was wrong and suddenly I just broke out in these tears and he got me to (the Ohio State University Medical Center AIDS Clinical Trials Unit) and that’s how it all got started.*

*He helped me, when we started dating, we got together about a month after I started taking it (medication). (He) had lived with it for 7 years, and helped normalize it, that it wasn’t this huge deal, just part of life.*

**Initiation of medications**

Participants began taking prescribed medications at various times depending on the year of diagnosis, their physical condition, their acceptance of being HIV positive, other life circumstances, and the ability to obtain medications. Half of the participants were diagnosed and began medications after the introduction of HAART in the mid 1990’s. There were other individuals who began medications before HAART. Participants who started taking medications at the time of diagnosis usually had a major illness episode, entered a clinical drug trial, or had a physician whose philosophy was to begin medications immediately upon diagnosis. Other participants started on
medications when they developed HIV-related symptoms or had low CD4 levels. A number of participants reported being unwilling or psychologically unready to begin taking medication for several years after their HIV diagnosis. A few participants did not start on medication right away for financial reasons:

_The reason I did not take the medication right away was because I didn’t have any way to pay for it._

Regardless of their circumstances all participants in the study eventually began taking medication for their HIV infections. Participants reported being keenly aware that starting on HIV medication meant making a life long commitment to drug treatment.

_I struggled with the fact that once I start this, this is going to be an everyday thing for the rest of my life and that was a big emotional struggle because I had to commit to making that personal commitment to myself._

**Incorporation**

The second phase to emerge was that of incorporation. This phase focused on the physical and emotional adjustments participants reported they needed to incorporate the HIV medication regime into their daily routines and enable them to move toward adherence. For some participants this phase of the process occurred at the same time while dealing with initial awareness of their HIV diagnosis. For others beginning medication and the associated incorporation phase of the adherence process occurred some time after diagnosis. All participants reported difficulty adjusting to the physical and emotional aspects of beginning to take HIV medication. For some individuals this phase was brief and relatively easy. Other participants reported that incorporating HIV medication into their lives was a very difficult and drawn out process with periods of adherence interspersed with periods of non-adherence before eventually perceiving
themselves being adherent. In some cases, the participants acknowledge that this phase took several years or longer before becoming adherent. Regardless of when it occurred or how long it lasted, the incorporation phase consisted of these themes: struggles, side effects, stigma, motivators, and always adherent.

Struggles

Most individuals reported struggling to incorporate the daily demands of a complicated medication regime as well as the ongoing emotional impact of making a lifetime commitment to being on medications.

_That is, then I worked at a hospital, and my time wasn’t my time. I couldn’t stop...when I was doing something._

_It was just horrible, terrible trying to work and deal with that._

_That was pretty difficult to adhere to because you had to take it like an hour, um, well, it was an hour that you couldn’t eat before you took it or two hours after, and your whole day was worked around that drug. And if you were late you had to wait a little longer and it was important to be timely on that._

For some, the struggle included trying to deal with resentment about the regimentation that adherence required:

_Initially for me, we’re talking regimentation, that was rough for me, and I mean I cursed for about 2 weeks. And a couple times, I was ready to say I’m done, I don’t want to do this anymore. Um, because whatever I do, I’ve got to be home by midnight because I’ve gotta pop those pills._

_I am a control freak, and that controlled me. I didn’t control it, it controlled me._

_I think that was the worst part for me was the regimentation. Um, at that point, I was working steadily for the theatre company, so schedules were completely crazy. You had to take them every four hours and that was like, you had to set the alarm, wake up in the middle of the night, pop some pills and then try to go back to sleep or stopping in the middle of a rehearsal because I had to go take a med. So it really took some doing it was, every four hours, that was rough, that was rough._
For some participants the early struggle to adhere was not successful due in part to problems with alcohol or drug use:

*I would be drinking, doing drugs, sleeping around whatever; it would be the last thing on my mind.*

*The only time I think I had a problem with adherence, was there was a time when I was partying a lot and drinking a lot, and some lost days, and that was really the only times I missed doses.*

*I didn’t adhere to them at all, hardly for the first ten years. And I was abusing my body with any drug you can think at the same time for about 20 years.*

*When I was drinking and druggin I chose not to take the pills.*

Other participants were unsuccessful in their early attempts at adherence for a variety of reasons:

*When it was all that confusing bullshit I didn’t take em a lot it was just so confusing like two hours before eating an hour after that was just too much.*

*Well, it was terrible, there was a huge DDI on this study, and huge horse pills, about that big around, and you had to chew them while drinking water, or try to crush them in water, it was terrible....that was probably the least adherent I have been.*

*The first one was Crixivan, and you had to take it two hours before or after you ate, and I am a flight attendant, and so sometimes that just didn’t work out for me.*

*Side Effects*

Most of the participants experienced some type of physical or emotional side effects as a result of taking HIV medication. These side effects varied in severity and duration with most dissipating within a few weeks of onset. A number of participants, however, described experiencing side effects of sustained duration. Earlier treatments (prior to HAART) seemed to have some of the worst side effects but several medications
associated with HAART (e.g. Sustiva, Crixivan) also had side effects that were both intense and sustained. Most participants describe being adherent despite the side effects and either just suffering through them or working with a healthcare provider to change the medications with the most untoward side effects.

Side effects of medication were difficult for almost all participants, especially those who began taking medications early on in the epidemic:

*I threw up every day on a daily basis and I had diarrhea for like 9 months there were times I would actually catch the pills as they were being expelled.*

*I started with AZT, it about killed me.*

*I had diarrhea for 8 years.*

Side effects made daily life difficult for many:

*You would have to go instantly to the bathroom and when you did and you were trying to work you know and that hit you knew to get to the bathroom.*

*When you are a flight attendant you can’t run away and go take your medication, because sometimes it makes you sick....that was sometimes a problem.*

For some, side effects made them question staying on their medications

*I was like, Man, this sucks. You don’t feel good already, and now you are taking something that is making you feel worse. I almost went off the meds as I thought at the time, at least that would take care of one of the problems.*

Others found side effects to be too difficult and actually quit their medications for a time:

*I started medication that would make me feel like climbing the walls you know I’d wake up freaking out and I had diarrhea and on and on so I stopped completely cause I thought you know what I’d just rather go than live like that.*
For many participants side effects led to changing the medications that were causing the problems:

*When I started out was on Crixivan, it just took one kidney stone, and I was like, SCREW THIS... (laughter) ...you (his physician) better come up with something else fast. He put me on Norvir with it, and said my body would excrete it faster.*

*I think it was the D4T that caused peripheral neuropathy and I lost a feeling pretty much below my knees... I didn’t even realize it until one day I looked down at my floor and there was blood on my wood floors and I had stepped on a splinter, and I didn’t know I had stepped on a splinter, and that was painful waiting for the nerve to grow back. And I was lucky that after the doctor took me off the drug that the nerve did heal itself.*

Almost all participants got over their side effects, found a way to minimize the side effects or changed to less troublesome medication.

*After the doctors kept asking how I was doing with my meds that I finally told him what problems I had. And we changed them and everything was fine.*

*I went to my doctor and I felt like I was defeated because I couldn’t take this one medicine she’s like oh no we’ll switch you to another one.*

*I’ve learned, instead of bouncing off the walls to sit down for a few seconds before just jumping out of bed like I used to, so I don’t fall flat on my butt.*

**Stigma**

All participants reported some difficulty dealing with the stigma, real or perceived, of being HIV positive and taking medications. The side effects associated with HIV medications and the challenges of incorporating medication into their lives were felt by many to threaten attempts to keep their HIV status hidden.
Stigma, related to letting others know their health status, could impact multiple aspects of their lives; such as employment, insurance, and relationships with significant others. Many participants reported believing that avoiding stigma was easier before they began taking medications:

*Why is this young, middle-aged person taking pills.*

*For me it (not needing medication) was like a little bit of denial because up to that point I had been undetectable (Viral load).*

Some expressed concern that side effects from medications might lead others to learn about their status:

*I got a mild form of that (rash) on my hands, and was paranoid that other people would know what was going on.*

Some participants reported that having to take medication was a constant reminder of their HIV status, a fact that they had been able to avoid thinking about until that point:

*It was a daily reminder of your status um, you can forget about it for awhile, but the time to take your meds comes, and you have to face it....*

For many participants this concern about stigma resulted in missing a dose or changing their schedule to keep their status and need to take medication hidden:

*Or you don’t take them because what happens if Joe Blow sees you taking them how am I gonna explain this.*

*You couldn’t explain to the relative or friend that that (holiday dinner time) wasn’t going to work in my favor,. So, um, you had to change your dosages to different times of day, not the dose but the time, and move things up and back.*

For others, the impact of stigma led to feelings of shame:

*I felt ashamed, I took my medications to work and I always had to hide, carry a bag, and sneak.*
Trying to avoid detection led many to adopt behaviors that would allow them to take their medications while maintaining secrecy:

- *I always put them underneath the table take out what I need and then cover my nose as I am putting them in my mouth so nobody knows what I am doing.*

- *Somebody finally told me to act like I had a headache so I just (grabs face) and throw em down.*

**Motivators**

Many participants reported certain motivating factors that helped them persevere through the difficult incorporation phase of the adherence process. For some participants other people and pets provided indirect help with adherence by being motivators:

- *I wanted to see my son graduate from school and college.*

- *All I asked God was to let me live longer than my Mom and my dog. That’s all I asked if they die before me and I die then I’m ok. But I take care of my mother right now, she’s ill. That’s all I asked.*

- *I am happier (with current partner) than I have been since all that happened, And I am not about to take the chance of getting sick because I didn’t take my meds and end up losing that because I want to be here to experience it.*

Others were motivated by people who are no longer living:

- *What helps keep me adherent and put me back on track is to remember the people that aren’t here anymore, and the fact that these drugs weren’t here for them. And I remember a lot of those people and everything that HIV has gone through, and the people have gone through in the last twenty some odd years...and I am thinking about people like, an ex of mine, thinking about him, and the what ifs....Like what if he had started taking medication earlier, would he still be here, and just thinking about the people that are gone, puts me back on track sometimes, Like, oh yeah, I need to be taking my meds.*

Some participants also reported fear of illness or death as a motivator for their adherence.

- *I don’t want to die yet, I have to stay healthy to stay alive.*
Originally what was helpful was the fact of not wanting to die, that was what really boosted me in to taking the medications as directed because I wanted to live.

In 1988 the only people I knew that had HIV, were getting ready to die, they looked in the stereotypical way, and I sure didn’t want to look that way. That’s my motivation.

I am not ready to die, and not in a position where I want to lose my health and have to suffer and uh, then blow away and die or whatever.

Others identified a feeling of obligation that helped to motivate them:

There a unspoken expectation like you know you need to be alive because we (others with HIV) need you at the table and we know if you do it we can do it just as I know that they did it and I can do it and so it’s this process of growth and moving.

Some individuals identified specific goals that they were working toward which served as motivators for adherence:

Well, I’m starting nursing school so that’s my goal.

I think right now my career motivates me too. I mean going to graduate school is a hell of a lot of work, and often times I feel like it is a selfish act, you know like I am taking so much and investing in me and he(his partner) is invested in it too, and there is just way too much invested in it.

Being Always Adherent

While a number of participants reported periods of non-adherence during their adjustment to being on HIV medications, many participants report being adherent from the initiation of medication despite experiencing difficulty during the incorporation phase:

I think it was hard to at the beginning because back then I was on medications that had to be refrigerated, well it was hard for me, because like you can’t put em in a baggy and you can’t put em in your
pocket cause after they warm up the medicine isn’t no good
any more so I always had a hard time with that, with the refrigeration
but I’m not on that medicine anymore but that was a real bad, that was hard.

I had almost died... because I was in the hospital and very sick with
pneumocystis... so I forced myself even though it wasn’t a pleasant experience, I
forced myself to take the medication when it was prescribed every day.

Well, with the study I was in, and AZT, back then, you had to take it often.
You had to take it like 5 times a day. So that was a struggle taking it that often.

I missed 5 times in maybe 12 years.

Four doses, four individual pills I’ve missed since I started my medication
in six years I’ve maybe, maybe missed three doses.

I’ve missed two maybe three since I started three years ago once I forgot and
went to bed.

Maintenance

Adherence to a daily medication regimen is not a static event rather it is a
dynamic behavior that must be maintained despite the ongoing challenges associated with
daily life. For participants in this study the emotional issues associated with an HIV
diagnosis have been replaced with acceptance and optimism. The difficulties of the
incorporation phase have given way to a more manageable routine driven by an
underlying belief in the efficacy of the medication and supported by significant others, an
effective relationship with a healthcare provider and the identification of memory aids.
The themes that emerged in the maintenance phase were: belief in medications,
reminders, routine, significant others, health care provider relationships, acceptance, and
positive attitude.
Belief in Medications

All participants reported having the belief that the medication they take is responsible for preventing their illness and death. Some participants reported using their lab values (CD4 count and viral load) as indicators that they are being adherent and that the medication is working:

*I know every few months I am getting labs, and so far they are always good. You know. That’s because I take the medication regularly.*

*I’ve gone from 189 to 814 its taken 12 years to get there.*

Belief in the effectiveness of medication and the need to be adherent was also illustrated with examples of others who were not adherent:

*One guy is 33 and had a stroke, the other is in his early 40’s and he is probably going to die. I mean that’s not because of HIV and the effects of it, but because he stopped taking his drugs.*

The belief in the effectiveness of medication also led to efforts by many participants to assure that medication was readily available:

*I always have my medicine with me. It sucks you know I would like to have nothing, just go but I always have to have it cause you never know if you’re going to have a flat tire or something.*

*I take all mine with me, because I am afraid of getting stuck without them.*

One participant reported that his current adherence is based, in part, on a fear that he might not have access to medications in the future:

*And for a period of time I may have to be without them, I don’t need to miss when I do have them.*
Reminders

Most participants indicated that remembering to actually take medication can be difficult

My only problem is that it has gotten so routine that sometimes, it is like 5 seconds later, I can’t remember if I took my doses.

Especially if you’re really busy and your working and you’ve got other things going on in your life and everything you do your like ok did I take it or not.

A number of the participants indicated that they use some type of pill container to help them keep track of and remember medication dosages:

I’m on a schedule, bought a plastic pill dispenser that has the dates on them, and refill it every Sunday.

I have a pill box. It has become a ritual and every Sunday morning I refill it. And I can’t ever forget about it, because it’s in my backpack and my backpack goes everywhere with me, and they jiggle, so there is that aural reminder as well.

There in a container and I know you know what, it’s just outta habit you know. Then its like, And I do question myself I’m like “did I take my pills tonight or not” so then I go look and sometimes they are still in there.

Many of the participants reported keeping their medication in places where they would see them and using that visual cue to trigger adherence:

I keep them out on the counter right next to the kitchen sink.

I keep them right by my toothbrush. I open the cabinet, I brush my teeth, I have my water, it’s all right there.

Mine sit in the containers that they come in on the left side of the sink.
Some participants have developed unique methods to help remember their doses:

I put em in sandwich bags and at night time my sandwich bags are in a container on top of the refrigerator and then in the morning I put them in the cupboard so then I know how many bags I had and when I have taken my medicine cause if I forget I can get into the cupboard and tell what day it is.

I live with Chap Stick. And I reach in my pocket all day, every day, any day, several times 7 days a week. I throw my pills in my pants every day....just habit, I have to take my meds when I eat, it doesn’t’ matter when I take them, but I live with Chap stick...I throw the stuff in my pocket every day, the pills are in my pocket all day, my reminder, and I don’t miss ever.

A number of participants reported that they don’t use any reminders to help them with adherence but have just developed a sense for taking the medications on schedule:

I know that I need to take them at dinner time and that is just in the evening.

I am pretty organized and used to taking them, it's like brushing your teeth. It’s the same thing every single morning.

Routine

Most participants talked about how they have incorporated the medication regime into their daily routine. For most this routine, which has developed over time, allows them to easily move through the day while incorporating their medication schedule around other activities of daily living:

I’m down to two pills twice a day before it was three pills twice a day take em at the same time every day and its just, almost like I take, like taking your morning vitamins I just, I don’t think about it too much.

It’s like eating....you just do it.

I get up, brush my teeth, take my pills, I go to bed, brush my teeth, take my pills. No matter where I was, my routine never changed.
It's routine, I wake up, I have my coffee, I take my pills, I go to work, come home, right before I go to bed, they are in the medicine cabinet, I take my pills.

Many participants acknowledge that medications are much easier to adhere to today than they were previously:

I’ve been adherent forever but it’s easier today.

I was taking them four times a day that was hard and now it’s just two times morning and night so it’s a lot easier today.

I think it is fantastic that three in the morning and three at night compared to what I used to have to go through.

Significant Others

Participants identified a number of factors which play a role in their ability to maintain adherence. Most identified significant others who play an important role in their lives. These included partners, family members, colleagues, their boss and friends at work, and support groups.

My partner is fantastic he orders all my meds, he takes care of it, you know he’s just there, boom he’s just there, he is behind me 100%.

They were supporting me and they were with me in my attempt to maintain which makes you feel like you are not alone and so when they are standing there with you it is a value to have people standing there with you and it makes you want to take these for sure.

I told my boss, and she was incredibly supportive, it shocked the hell out of her, but, anyway, she was really supportive.

I was fortunate when I found out, um, I didn’t live far from my parents, and I had my partner and my ex-partner, because the first 6 months was real had.....for the first three months, I couldn’t even bathe myself.
Health Care Providers

All participants spoke at length about their relationships and interactions with health care providers. Most participants have, at some time or other, been involved in the AIDS Clinical Trials Unit at The Ohio State University in Columbus.

_I was interested in being a guinea pig. The benefit was that I was able to get my blood checked monthly at the time, so I was able to monitor my progress and approve or decline any therapy. I felt that way I would be on the cutting edge._

All participants spoke highly of their health care provider, who almost always was a physician:

_I have complete 100% confidence in my doctor....he’s extremely supportive, kind of like a therapist, his bedside manner is great._

_I am very lucky, and I have a really good doctor._

A number of participants reported that being able to depend on their health care provider is an important aspect of their relationship:

_My friend takes me into the hospital, and she calls my doctor. He says okay, I am on call at the hospital, what you do is when you get to the hospital, have them page me before you are admitted. And I don’t know too many people that have that kind of doctor...so I am lucky._

_If I develop bronchitis or flu or whatever, she maintains about 3 open spots.....and is aggressive, with whatever, it’s like I have her attention no matter how often I need to go._

_I lost my luggage, sure enough, he (HCP) had them air freighted to me the very next morning I had pills_
Many also reported that they felt their health care provider was truly concerned about them as a person:

"He is very professional, very laid back, even when I was in the hospital and I didn’t want to get tested, he would stop by after rounds every morning just like he was a friend of yours, you know eventually I think there was a couple mornings he spent at least an hour with me."

Several participants reported expressions of concern by the health care providers was very helpful to their adherence:

"He does ask me about the effects of the drugs and things like that. So he is concerned about that, so if I am having some kind of sickness or lightheadedness or spaciness from the drug, he wants to know, so he can possible change the drugs which helps me adhere to the regime."

Many individuals have had a long term relationship with the same healthcare provider:

"I have seen my doctor for over ten years, and at the ten year date, I gave him a tie as an “anniversary gift” and so we always chuckle about that."

Many participants reported that they believe the relationship with their healthcare provider requires that they be an active participant

"I think that I need to be the best patient I can be. I think if I resist in any way, that is not reasonable...I am the one that is going to miss out. I just want to cooperate.

"I think it is important to develop a relationship with them, and work with them, and see them as an ally in my overall health, so I don’t look at them as being against me, but work with them is more beneficial to me. I include them in my team, and I try to share everything with them."
Some participants spoke about specific characteristics of the health care provider that they found to be helpful:

I look at them like a professional relationship in a way that I am here for a service and need this provided....if I felt like he didn’t care, or didn’t fulfill that, I would chose someone else.

I’ve had the same doctor since diagnosed, and we have a good relationship.

It’s a gay doctor, and I always felt like I was either going to find someone who knows a lot about HIV or they are gay. They wouldn’t be as judgmental.

My doctor respects me...as I respect him. And his bedside manner is excellent, and that makes a huge difference, it’s like I am sitting with a friend talking.

I am a control freak, he gives some of the power back to me....the decision making is when I sit down and have his attention and it feels very, very good.

Most participants reported that they trust their health care provider’s directions and follow them as closely as possible:

If my doctor said that I had to climb to the top of a building every day to take my medicine, and stand on one leg, I would, that’s the way I am.

A few participants spoke about their attitudes toward changing doctors if necessary which also suggested a sense of empowerment in the relationship:

It is good to have a good doctor, but if you’re not happy, switch. I’ve had a couple of doctors I would fire...that’s it, done, and I walked out.

While most participants reported having a very positive and supportive relationship with their healthcare provider some identified a kind of tough love approach to their situation:

When I got sick the last time it was very bad I couldn’t walk or couldn’t talk or anything and he was in the room and this is what helped me is getting on the medicine he told me this is exactly what he said he said Ron there is no damn sense of you being in this situation and he said you do exactly what I tell you to do or he said I’m going to let you die.
While participants mostly reported having a very supportive and positive relationship with their current healthcare provider, a few illustrated past experiences that were not supportive or positive:

*I had the one who told me I was going to die right at the beginning.*

*He diagnosed me and then he wanted to put me on something and I was flipping out I called that doctor at his job and he got mad and he said “look when are you going to get a handle on this”? I went “more than ten minutes in your office dude”.*

Acceptance

Despite early struggles for many, all participants in the study considered themselves to be adherent currently and expressed an acceptance and “ownership” of their HIV status and the need to be on medication. Most have reached a point of acceptance and have committed to being adherent:

*There’s an acknowledgement in owning the disease that I never did until I, I started medications. The hammer just came down, got to take these meds, you can’t miss and in my three years I, I know I haven’t missed more than three times.*

*I know that until there’s a cure I need to take these at certain times every day. I guess I’m trying to say it doesn’t bother me.*

*I mean maybe its denial a little bit but when you first take that first medication that’s when you say this is the rest of my life and I’m positive.*
For some participants dealing with drug and alcohol problems was an important step in becoming adherent:

*I’ve been clean and sober for almost two years so that’s all behind me (applause), it just a lot easier when you are clear headed to you know, probably 100% now, I can’t think of the last time I missed a dose. The last one I missed was probably years ago when I was well, high.*

**Optimism**

Despite their HIV status and the need to be on medication, participants in the study were generally optimistic about their situation. Many compared HIV with other health conditions:

*You know I think I’d rather, if I was going to have anything right now I’d rather have HIV other than sugar diabetes like my brother, its awful for him.*

*I know people who take meds for other problems, heart problems and stuff, so I do the same thing.*

Other participants saw their personal situation as much less dire than that of other people with HIV:

*I had a good friend who became really sick really fast, um in a period of like 3 months he was hospitalized, dialysis, and had advanced to AIDS like to the point where we didn’t know if he was going to come out of it, and it made me really appreciate how lucky I am and how easy I have it.*

*The way I looked at it at the time was that I was very fortunate, because what those people wouldn’t have given to have access to what I have access to….so why feel sorry for myself that I have to take medicine, when people that died would have given anything, especially my brother would have given anything, to have had access to what I had access to at the time.*
Many reported having a positive attitude about the time and place in which they find themselves, in relation to being positive:

*If you want to be HIV infected, Columbus is a good city to be infected in, thanks to the history of some people.*

*I felt very fortunate to come into it (being HIV infected) when I did.*

A number of participants reported being optimistic about the changes that have occurred related to disease management:

*Every so often there is a big advance, and I have been lucky enough to see that, and we all have. And I have just I guess I am hopeful to be around for the next big advance and everything is different and better. That’s enough for me to want to be around and stay healthy.*

*The medications that are so much easier to take, you are just wide open with medications, it’s unbelievable.*

For many participants, optimism took the form of hope for the future and the hope that their struggles might help others:

*We all stay around long enough the doctors and researchers will be able to figure out why we have been around so long and maybe come up with things for the future, like maybe a vaccine that will help future generations and stuff.*

*I am doing a lot of things with bone scans, muscle mass whatever they need, because if it helps somebody down the road it helps.*

*The reason I started taking drugs and volunteering for the drug study was if I was going to die of this I may as well make some use of.*

Several participants reported that their own struggles have resulted in a desire to reach out to help others experiencing similar issues:

*I work with newly diagnosed and I work with people who are dealing with the issues that I’ve already gone through and you know but I’ve done it.*
I want to be a nurse someday... I’ve always felt it is easy for someone to read about a disease, but to actually have had suffered the disease, but I think this disease gives me an up on someone who is straight, or clueless about the lifestyle or disease, and trying to treat someone or be supportive. By being positive, and having lived with the disease you can contribute something that you just don’t get if you have never had it.

Perceived Facilitators to Adherence

The perceived facilitators were present in the three phases of the adherence process. Most of the facilitators were discussed in the maintenance phase. The facilitators were belief in the medications, making a commitment to taking the medications, dealing with the side effects, developing strategies for fitting the medications into their lifestyle, having motivators, support of significant others, a supportive relationship with their health care provider, and a feeling of optimism and wanting to keep on living.

Perceived Challenges to Adherence

Participants reported a number of challenges to becoming adherent. Many of these challenges have been discussed previously in the three phases and were successfully negotiated by study participants. Challenges such as stigma associated with HIV diagnosis and HIV medications, access to medications (financial and physical), substance abuse, untoward side-effects, complicated dosing schedules, denial and depression all played roles in the participant’s early struggles with medication adherence. Despite early challenges, all participants reported that they are currently adherent, a claim that appears
to be supported by surrogate measures of adherence (CD4 counts and viral load measures). While all participants report current adherence to their medication regimen, many also report that they continue to encounter challenges to maintaining that adherent behavior.

Many participants reported that the relative ease of current dosing schedules (once or twice a day) is a bit of a conundrum. The current schedule is so simple compared with the extreme requirements (multiple doses, multiple times, often with dietary restrictions) of earlier regimes that some participants reported that they are at times challenged to remember whether or not they have actually taken a dose:

> *My biggest problem is after I’ve been awake for a couple hours I’m like “did I take my pills today”?*

> *Especially if you’re really busy and your working and you’ve got other things going on in your life and everything you do your like ok did I take it or not.*

> *My only problem is that it has gotten so routine that sometimes, it is like 5 seconds later, I can’t remember if I took my doses.*

Many participants reported that they error on the side of caution and, rather than assuming they took a questioned dose and risk missing it, took an extra dose:

> *I probably overdosed myself you know, I’ll take em and then ten minutes later you know I’ll think did I take em?*

Some participants reported that the difficulty remembering specific doses provided the impetus to engage in problem solving behavior:

> *About six months ago, I realized I took an extra dose. I thought maybe I had, and finally took out and counted all my pills and indeed had, so that same day I went out and bought one of those pill containers.*
An on going challenge reported by many participants related to balancing other parts of their lives with the need to take medications. For some participants this was a challenge because of social activities:

*The biggest thing that comes to mind is um, evening dosages of medication. Like, ‘I’m sorry I can’t stay tonight, because I have to go home and take my pills.*

*If it is time to take them, it’s 9 o’clock in the evening and you are having cocktails with somebody or at movie with somebody, it’s like okay, I am going to be 3 hours late, because it’s a 3 hour movie and now I need to take my pills.*

*The main problem I have is the evening pill. If you are out visiting and forget to bring them with you, I just skip it, and that very rarely happens.*

*Going out, when I have gone out with friends and made a really long night of it, and the suns coming up and you realize, I need to go home and take my meds.*

For some participants the challenge related to continued alcohol use:

*On the rare occasion, I might drink too much and skip a dose, because my stomach just wasn’t up for it, just feeling crappy and didn’t want to add anything else to it...*  

*Unfortunately, I will admit ....if I have had too much to drink, sometimes at night I won’t take it.....but happens very rarely.*

Other participants reported current challenges related to work:

*At 11 o’clock I can be meeting with a customer, I can be in a meeting, you know, like, it’s 11, 11:15, and 11:30 comes, it’s basically just being busy. You can’t take it there you’re caught up in something, like if the meeting is over at a quarter till 12, then you take it....that’s probably what’s caused me to miss, or just being busy or so caught up and time goes by.*

*There are some countries that if you are HIV positive, you can’t get in.. and that’s a bit of a problem, because (as a flight attendant) you have to explain it to your supervisor because if you get to customs when you land, and if they don’t allow that, they will send you right back, and it can be big problems, so um, I try to work that out, because there are a couple countries that won’t let you in.*
Some individuals reported that medication side effects still present a challenge at times:

There’s been a couple of times when I didn’t have time to eat, and I will throw it up. And it’s still solid, and you have pretty much missed your dose, and I don’t have more with me.

If I am going to be going out I try to space the meds out so if it is going to happen (diarrhea), it’s going to happen now and not at 9:00 in a crowded restaurant on a Saturday night.

Is it really worth taking these pills for the side effects, and then its like well you know what yeah it has to be but you do go through I did go through that its like you know what I don’t want this stomach but I want to live.

Several of the participants reported that travel presents a challenge:

The main (challenge) for me is now I travel a lot and they have lost my luggage a couple of times, so that was tough.

Maintaining a relationship with a health care provider was a challenge for some study participants, due in large part to the recent departure of a key HIV physician from the area. And, some participants reported that unforeseen events in daily life can, at times, present challenges to their ability to maintain adherence:

Sometimes I can get lost for hours and just lose time, be doing something....

I can just get too preoccupied, but have never deviated from the schedule for more than a few hours.

I’ve been busy, overslept and just tore out the door, but it doesn’t happen frequently.

Sometimes, I just forget.
Discussion

Since early in the AIDS epidemic, researchers have studied adherence behavior in populations of individuals living with HIV. The introduction of HAART in the mid 1990’s, however, energized this particular area of research. HAART allowed for the conceptualization of HIV as a chronic illness, but only if associated with high levels of medication adherence. Much of the HIV-related adherence research has focused on identifying predictors of non-adherence using subjects with sub-optimal levels of adherence. The current study represents one of the few qualitative studies exploring HIV-related adherence from the perspective of individuals who report high levels of HIV medication adherence (Gray, 2006; Lewis et al, 2006; Malcolm et al., 2003). Of the four studies, this was the only one to use a homogeneous sample.

The participants in the study perceived themselves as being adherent to their prescribed treatment at the time they participated in one of the six focus groups. All of the participants had been diagnosed as being HIV sero-positive for a minimum of a year and on medications for at least nine months. Surrogate measures of adherence used were self-reported adherence over the three days immediately preceding the focus group interview and self-reported lab values. Both measures suggested a high level of adherence for most participants. Based on self report, all participants in the study were 100 percent adherent in the 24 hours prior to participating in their focus group. One participant reported missing one medication dose in the prior 48 hours and two participants had missed one dose in the prior 72 hours. Self-reported laboratory values also suggested high adherence rates. Almost all (92%) participants reported that their
current viral load is undetectable. The current average CD4 count was 530 in contrast with a lowest average CD4 count of 196 for all participants.

The study was guided by the Ickovics and Meade’s (2002) determinants of adherence model (see figure 1). This model has five major concepts: patient characteristics (socio-demographics and psychosocial factors); disease characteristics; treatment regimen; patient-provider relationship, and clinical setting. In terms of the patient characteristics the socio-demographic factors of the study participants were white males who ranged in age from 32 to 59 years, employed that self-reported being adherent. These characteristics are congruent with studies that indicate that male gender, white race, older age, higher incomer, higher education and literacy correlated with higher levels of adherence (Chesney et al., 2000; Gifford et al., 2000; Kleeber et al., 2001).

Multiple psychosocial factors were present in the experiences of some of the participants that included some mental health issues, alcohol and drug use, struggles, body image, motivators, and optimism. Almost all participants perceived social support as being important in being adherent. In terms of disease characteristics, there was diversity in the health issues experiences from being critically ill in an intensive care unit to no HIV-related illness. The treatment regimen was a major factor in terms of being adherent in terms of side effects of the medications, complexity in terms of number and times per day, food restrictions, and fitting into one’s life style. All of the participants mentioned the importance of having a good patient provider relationship in being adherent. In terms of clinical setting that refers to access to reliable care was considered necessary by many of the participants and was a reason for finding a different doctor for their care. In this study all of the concepts were considered and emerged as being part of the process of
becoming adherent. The use of the model needs to consider the temporal dimension as the individual is evolving and changing as interact with one’s contextual environment.

Based on the findings of the study would consider the development of a model based on the processes, stages, and themes that emerged in this study. The model would be able to take into account the dynamic, temporal aspects of adherence as individuals experience their illness trajectory and life development. Such a model could account for more of the variation in individual levels of adherence. This model may also provide direction for timing of interventions to coincide with specific challenges in the adherence trajectory.

This study was similar in terms of some demographics and some of the health history to three other qualitative studies of individuals with high levels of adherence to HIV medications (Gray, 2006; Lewis et al, 2006; Malcolm et al, 2003). Each of these studies used purposively selected samples of individuals with high levels of adherence who had been on HIV medications for a minimum of three months. There were major differences in demographic variables between the studies. This study had a predominantly white sample of employed, gay males who reported a yearly household income above $50,000, and most lived with a partner, roommate, or children. Gray (2006) had an ethnically diverse sample of 11 persons living with HIV that included almost an equal number of males and females. They were mostly low income, unemployed and either widowed, divorced or single. Lewis and colleagues’ (2006) sample of 13 participants was mostly white males who were low income, unemployed, and most were classified as being disabled. The participants were evenly split between persons who were single, widowed or divorced and those living with a partner. Malcolm
and colleagues’ (2003) study had a sample of predominately current and former substance abusers who were mostly white male (64%) participants. They did not report ages for their subjects. The ages of participants in the other three studies were comparable. None of the other studies reported time since HIV diagnosis or time between diagnosis with HIV and beginning medication, however Lewis et al. (2006) reported a range for time on medication (9–144 months) that was not reported in the other two studies (Gray, Malcolm et al.). In this study the range of time of treatment ranged from 9 to 440 months.

All four studies focused on adherence with different research objectives and methods. In this study the investigator used focus groups and a background information form to describe the medication experiences of gay, HIV positive, males that self-reported being adherent to their HAART regimen. Gray (2006) used individual interviews and a demographic and medication adherence form in her grounded theory design to understand becoming adherent from the participant’s perspective. Lewis et al (2006) used semi-structured interviews, data from a larger study in which the participants were enrolled, and electronic event monitor to describe their medication behaviors and attitudes. Malcolm et al. (2003) used semi-structured interviews to compare excellent and suboptimal adherers to HAART. In addition, they administered two drug screening questionnaires and a depression inventory. In all four studies the questions used in the focus groups or individual interviews were developed by the investigators.

In the investigator’s study, during the focus groups, participants were asked to share when they were diagnosed with HIV, what it was like when they began taking HIV medication, what taking medication is like now, if they found anything to be helpful or
problematic with regards to taking medication as prescribed, and about the relationship with their healthcare provider. Three main phases emerged from the data that were initiation, incorporation and maintenance. Each phase also included several themes. The themes in the initiation phase were learning the diagnosis and initiation of medication. The second phase, incorporation, includes the themes of struggles, side effects, stigma, motivators and being always adherent. Maintenance, the final and ongoing phase of adherence behavior includes the themes of belief in medication, reminders, routine, significant others, relationship with healthcare providers, acceptance, and optimism.

The initiation phase included learning the diagnosis which was unique to this study in comparison to the other qualitative studies regarding adherence. The first theme of Gray’s study, choosing life, mentions the actual diagnosis, however, it is used more to indicate a starting point for medication and is not addressed as a unique situation. Neither of the other two studies addressed the topic of diagnosis (Lewis, et al 2006; Malcolm et al, 2003). While some participants in the study reported initiating medication upon diagnosis (typically because of an HIV-related illness and/or hospitalization), others were afforded some time between diagnosis and treatment. Most participants reported having some emotional difficulty accepting their diagnosis. The most commonly reported reaction was depression which, along with other emotions, such as denial, anger, and self-blaming, have been shown to have a negative correlation with adherence behavior (Gonzalez et al, 2004; Malcolm et al., Wagner & Ryan, 2004; Power et al, 2003). For those individuals who initiated medication upon diagnosis the struggle to be adherent was often complicated by acute illness and the grief work associated with learning the diagnosis.
The second phase, incorporation, includes the themes of struggles, side effects, stigma, motivators and being always adherent. This phase deals with the time in the process of becoming adherent during which individuals adjust to the physical and emotional demands of incorporating medication into their daily lives. Incorporation is similar to Gray’s themes of “choosing life”, “riding it out”, and “figuring it out”. The themes of struggles, side effects, physical and emotional reactions, and motivators were mentioned in the other two studies (Lewis et al, 2006; Malcolm et al 2003).

Almost all participants reported having difficulties incorporating HIV medications into their daily lives. These struggles with adherence behavior are commonly cited in the literature and are in part responsible for a less than optimal adherence for a significant number of people on HIV medication (Eldred, Wu, Chaisson, Moore, 1997; Halkitis, Parsons, Wolitski & Remien., 2003; Lewis et al., 2006; Patterson et al., 2000; Singh et al. 1996, ). Remaining adherent despite side effects, and viewing side effects as a temporary precursor to improved health, are behaviors similar to those reported in two other qualitative studies (Gray, 2006; Lewis et al). Substance abuse and decreasing or abstaining from substance use were issues also addressed by two other studies (Gray, 2006; Malcolm et al., 2003). Stigma has been found to be negatively related with adherence (Vanable, Carey, Blair & Littlewood, 2006; Rintamaki et al., 2006) and was identified by participants in the investigator’s study as one of the struggles associated with the incorporation phase.

Participants identified a number of factors, which had a supportive or motivating influence on their desire to incorporate adherence behavior into their lives. Included among the identified motivators were other people, both living and dead, pets, fear of
illness and death, a sense of obligation to others and specific goals, such as education. While many participants were unable to maintain adherent behavior while faced with struggles encountered during the incorporation phase a number reported always being adherent. These always adherent participants reported experiencing similar difficulties to those who were unable to maintain adherent behavior. Those identified as being always adherent, however reported riding out some challenges, such as side effects, or effectively coping with other challenges that temporarily derailed their peers.

The last phase, maintenance, represents an ongoing, evolving state. Adherence is not a static state but rather is a dynamic, evolving process supported by maintenance behavior in negotiating the ongoing challenges of daily life. In the maintenance phase the difficulties of the incorporation phase give way to a more manageable routine. The themes in the maintenance phase were belief in medication, medication reminders, routine, significant others, relationship with healthcare provider, acceptance, and optimism. Gray’s themes of “sticking to it” and “realizing the benefits” are congruent with the maintenance phase themes. Also Lewis et al’s (2006) main theme “successful medication management” and the three sub-themes have similar descriptions to the maintenance phase in this study. Malcolm et al (2003) had some similar findings in terms of beliefs about adherence and medications, social support, and relationships with health care providers. Participants in these other studies described the desire for physical health and a long life as motivators of adherence behavior, but did not identify concern for other individuals as a motivating factor as in this study.

All four studies focused on the experiences of individuals who perceived themselves as successful with their adherence behaviors. This is a shift from the
predominant approach to studying experiences of individuals with sub-optimal adherence. Despite differences in the socio-demographic characteristics of the samples in regard to gender, ethnicity, and economic status, these four studies share a number of similar findings. Participants in all studies reported a strong belief in the efficacy of their HIV medication and a commitment to being adherent. Participants cited improved laboratory values as a motivator for continued adherence and evidence that medications prevent illness. These individuals also reported continuing to take medication despite side effects, which were often viewed as a temporary hardship to be worked through. Participants also reported social support which they described as helping their adherence behavior through the provision of general (non-medication specific) support. Finally, participants all described having a positive relationship with their healthcare provider. This relationship was often seen as a trusted partnership requiring active involvement by both the healthcare provider and the patient.

There were also differences between the four studies. While all four studies used qualitative methodology, the sample in this study was more homogenous than the other three. The participants were of higher socio-economic status, spoke at length about their HIV diagnosis and the associated difficulty with learning they were HIV positive. The other studies used the initiation of medication as the starting point. While subjects in all four studies identified social support as a factor related to adherence they did not indicate that living for other people was a motivator for adherence. In fact, Malcolm and colleagues (2003) found this motivator common among their sub-optimal adherers.
Participants in the investigator’s study frequently indicated that concern for other people (and pets) as well as a sense of obligation to survive for people who had died served as motivators for ongoing adherence behavior.

The experiences of participants are consistent with studies showing that grief, such as that associated with the diagnosis of a serious, possibly life threatening illness, like HIV, presents a major challenge to an individual’s coping skills and requires a period of adjustment as the individual encounters a variety of emotions (Neimeyer, 2000). What makes participants in this study different from many others living with HIV is that they have successfully incorporated their HIV medication regimen into their daily lives and have been able to engage in ongoing, high level adherence behavior.
CHAPTER 5

SUMMARY OF THE STUDY

The purpose of this study was to describe the medication adherence experiences of HIV positive gay men who self reported being adherent to their medication regimen. The secondary purposes were to describe what these men perceive as the facilitators of their medication adherence and to describe what they perceive as their challenges to medication adherence. A high level of medication adherence is necessary for viral suppression and reductions in HIV-related morbidity and mortality (Arnsten et al., 2001; Arnsten et al., 2002; Bangsberg, Hecht, Charlebois, Chesney, & Moss, 2001; Mostashari, Riley, Selwyn, & Altice, 1998; Patterson et al., 2000). The study was guided by Ickovics and Meade’s (2002) determinants of adherence model.

A descriptive, cross-sectional research design, employing focus group methodology, was used to study HIV positive men who self reported current adherence to their HIV medication regimen. The inclusion criteria were: (1) HIV sero-positive, status known for at least 12 months, (2) currently employed, (3) 25 years of age or older, (4) currently taking anti-retroviral medications, (5) perceived (per self-report) being adherent to the HAART regimen, (6) speaks, reads, and understands English, and (7) agreed to be in the study.
The research prospectus was approved by The Ohio State University Behavioral and Social Institutional Review Board prior to conducting the study. The study involved each participant to complete a background information form and be in a focus group. The questions for each of these were developed by the investigator. The main source for recruiting participants was at the King Avenue United Church through fliers, church bulletins, and newsletters. Potential participants contacted the investigator and then were screened to assure compliance with study inclusion criteria. If an individual was eligible for being in the study, the investigator explained the study in more depth and scheduled a time for him to participate in a focus group.

A total of six focus groups were conducted that each consisted of four men who met the study criteria. Participants provided written informed consent and completed a background information form prior to participating in an audio-taped focus group. Each focus group lasted approximately 90 minutes. Each focus group was audio taped that was transcribed by an assistant. Data was coded and assigned to sub-categories in keeping with the primary objectives of the study: to describe the medication adherence experience of HIV positive men who report successful adherence behavior; to describe what participants perceive facilitates medication adherence and; what participants perceive as challenges to adherence. All interview transcripts were coded by the investigator and his advisor. These coding schemes were compared for to determine congruence between coders. Focus group interviews continued until, by the sixth interview, no unique codes were emerging from the data. Descriptive statistics were used to analyze and report demographic data.
The sample was comprised of 24 HIV positive gay men that ranged in age from 32 to 59 years, with a mean age of 45.34 years (S.D. = 1.54). In regard to ethnicity, 23 were Caucasian and one was African-American. Nine participants were partnered and lived with their partner. Ten participants lived alone while five lived with either a roommate or their children. Sixteen (67%) participants reported personal incomes greater than $25,000 and 19 (79%) reported a household income over $25,000. The majority of the participants had a household income over $50,000.

Time since diagnosis with HIV averaged 10.1 years and the mean time between diagnosis and starting drug therapy was 2.25 years. The average number of years on medication for HIV was 8.4 with a range from 9 months to twenty years. Eight (33%) participants reported having been hospitalized at some point for HIV-related problems. Twenty two (92%) participants reported currently having an undetectable viral load. The average current CD4 was 530.64 (S.D = 196.58) compared to an average low of 196.63 (S.D. =169.63). Self-reported adherence to HIV medication was 92% for the past three days, 96% for the past two days and 100% for the past 24 hour period.

None of the participants reported daily alcohol use, however, 11 reported drinking once or twice a week. Six participants reported no alcohol use at all. Most (79%) participants denied using illicit drugs. No one reported using illicit drugs on a weekly or daily basis.

From the data analysis a conceptualization of adherence as an evolving process comprised of three phases emerged. The three phases were initiation, incorporation and maintenance. Within each phase a number of themes were identified. Some themes were unique to a specific phase while others reoccurred throughout the adherence process.
Also challenges and facilitators of adherence were identified. Some challenges and facilitators were unique to a specific phase while others reoccurred throughout the adherence process.

The initiation phase focused on learning the HIV diagnosis and starting medication. The themes associated with the initiation phase were “learning the diagnosis” and “initiation of medication”. The theme “learning the diagnosis” focused on emotions related to the diagnosis, such as depression, denial and anger and associated behaviors. The theme “initiation of medication” focused on the time participants began to take prescribed HIV medications. This initiation occurred at various times depending on the year of diagnosis, physical condition, their acceptance of being HIV positive, other life circumstances, and ability to obtain medications.

The incorporation phase focused on the physical and emotional adjustments individuals made to incorporate HIV medication into their daily lives and move toward medication adherence. For some individuals this phase was concurrent with “learning the diagnosis” for others it occurred some time after diagnosis. All participants reported difficulty adjusting to the physical and emotional demands of HIV medication. The incorporation phase was brief and relatively easy for some and very difficult and drawn out for others. The themes associated with the incorporation phase were “struggles”, “side effects”, “stigma”, “motivators” and “being always adherent”. The theme “struggles” focused on logistical and emotional aspects of incorporating the new regimen as well as the difficulties related to substance abuse. The theme “side effects” focused on physical and psychological side effects. Most participants reported some unwanted alteration in physical or mental function secondary to HIV medication.
The theme “stigma” focused on real or perceived stigma of being HIV positive and taking medications. All participants experienced some difficulty dealing with stigma. Stigma motivated attempts by some to conceal HIV status which became more difficult upon starting medication. Attempts to conceal status resulted in purposely missed doses.

The theme “motivators” focused on what maintained perseverance despite difficulties encountered in the incorporation phase. These included other people (both living and deceased) and pets, fear of illness or death, feelings of obligation, and specific goals.

The theme “being always adherent” focused on participants who were able to maintain adherence despite encountering challenges that resulted in non-adherence in others.

The maintenance phase focused on the ongoing behaviors and challenges identified with maintaining adherence behavior. The themes associated with the maintenance phase were “belief in medication”, “reminders”, “routines”, “significant others”, “healthcare provider relationship”, “acceptance”, and “positive attitude”.

The theme “belief in medication” focused on the beliefs of all participants related to the efficacy of their HIV medication in preventing illness and death. These beliefs were strengthened by positive changes in laboratory values and observing illness in individuals perceived as non-adherent.
The theme “routine” focused on the incorporation of the medication regimen into the daily routine. This routine minimizes the impact of medication on life but maximizes adherence. The theme “medication reminders” focused on physical and mental cues used to remember medication doses. Most utilize some type of reminder.

The theme “significant others” focused on the support received from others in their social network, typically partners, family, friends and work colleagues, which was perceived as helpful in coping with daily challenges and maintaining adherence.

The theme “healthcare provider relationship” focused on aspects of the relationship between the participant and his primary healthcare provider (mostly a physician). This relationship was universally viewed as positive and significant in relation to ongoing adherence.

The theme “acceptance” focused on the attitude toward both the HIV diagnosis and being on medication. Most expressed ownership of both their illness and regimen.

The theme “optimism” focused on the attitude expressed to some degree by all participants. The impact of HIV was mitigated by comparing it to other illnesses, by comparing themselves to sicker people, by focusing on positive developments in treatments, and through altruistic thoughts and behaviors.

This study is similar to three other qualitative studies which also focused on the experiences of individuals who perceived themselves as successful with their adherence behaviors (Gray, 2006; Lewis et al, 2006; Malcolm et al, 2003). Participants in all studies espoused a strong belief in the efficacy of their HIV medication and a commitment to being adherent. These individuals also reported continuing to take medication despite side effects, which were often viewed as a temporary hardship to be
worked through. Social support, described as helping adherence behavior through the provision of general (non-medication specific) support, was common to participants in these studies. Another major theme in all studies was the relationship with a healthcare provider, which participants in each study described as very positive. It should be noted that, despite differences in the socio-demographic characteristics of the samples in regard to gender, ethnicity, and economic status, the findings are very similar.

The findings of this qualitative study, which cannot be generalized beyond the sample, describe adherence as a process rather than a static behavior which one achieves in a once and for all fashion. This process begins upon diagnosis with HIV. The emotional work needed to incorporate knowledge of one’s HIV status can compound the struggle to become adherent when diagnosis and initiation of treatment are concurrent. The process of adherence, like most behavioral change, is one of trial and error for many individuals. While the individuals in this study identify as being currently adherent, they all took unique routes to achieve that behavior and all describe daily challenges to its ongoing maintenance. Because adherence is a not a static behavior there are no guarantees that those who are striving to become adherent will not reach their goal nor those who currently identify as being adherent will remain so without continued effort.

Limitations of the Study

There are several limitations to this study that must be acknowledged. As a qualitative study with twenty-four participants, the findings cannot be generalized and are limited to describing the medication adherence experiences of the participants. Findings are also limited by purposive sampling which limited the study to currently employed men. Additionally, all subjects identified as being gay and all but one participant was
white. Assessment of individual adherence was based on self-report for the three days prior to each focus group. Laboratory values (CD4 counts and viral load measures), which have been used as surrogate measures of adherence in other studies, were also obtained via self report and not directly from objective data.

*Implications for Research*

Ongoing adherence research is needed to further identify factors that can help individuals deal with the struggles of incorporating a medication regime into daily routines and to support successful maintenance of that behavior. The adherence experience of the men in this study as well as the participants in similar other studies followed a process-like trajectory. Research is needed to further explore the concept of adherence as a process, specifically what phases make up the process. A phased process could be supported by various interventions depending on the tasks associated with each phase. To this end, longitudinal studies, beginning with the time of HIV diagnosis, are needed to examine the process and to identify those points in the trajectory possibly amenable to intervention. More retrospective research is needed to examine the adherence process of currently adherent individuals. Such studies can help to further define the adherence process and identify barriers and facilitators of the process over time. Such research is needed using a variety of sampling schemes to capture information about the experiences of the range of individuals impacted by HIV.

The investigator of this study identified several potential research topics of interest during this study. There does not appear to be any research on the validity of self reported laboratory values (such as the CD4 and viral load counts used in this study). It might be of value to examine the accuracy between actual and reported laboratory values.
It might also be valuable to identify if the accuracy of reported laboratory values has any correlation to adherence as one might assume that an individual who more closely attends to his laboratory values might also be more adherent to a medication regime. This could potentially provide another surrogate measure of adherence. Another research interest would be the examination of the adherence process in unique groups such as those in isolated rural settings, to understand how changes in certain socio-demographic factors impact the experiences of such individuals. A final question of interest to the investigator is the role of more enigmatic factors, such as subjective or existential well being in the process of becoming adherent. Increasing our understanding of the role of such concepts adds to the overall understanding of this very complex and very important health behavior. Understanding is a necessary precursor to the possible development of therapeutic intervention.

**Implications for Practice**

What can be taken from this and similar studies, is that adherence is a complex behavior that is impacted by a myriad of unique factors. While generalization from such studies is not appropriate they do provide for insight into certain experiences. For the participants in this study the time of diagnosis with HIV was difficult and required some processing. The expectation that a person can successfully initiate a complicated medication regime at the same time they are processing information related to diagnosis of a serious medical condition, especially without any other assistance, may be unrealistic. What the experiences of these men suggest is that the clinician needs to be aware of the difficulties encountered at various points in the adherence trajectory and provide support and possibly intervention to bolster the patient’s ability to manage these
challenges. As evidenced in the experiences of these men as well as the body of literature, adherence behavior is a path dependent phenomenon that suggests an individualized approach to the assessment of the patient’s situation as well as the development of interventions to help identify sources of and overcome challenges to adherence behavior. Key individuals, often lay people with characteristics similar to the patients, can play a major role in helping the patient accept their diagnosis and incorporate a medication regimen into their daily lives. A person who reports adherence may not be far from becoming non-adherent. Individuals who are adherent may be struggling with the same issues that non-adherent individuals encounter. These struggling adherers, might only be a few stressors away from non-adherence, should be assessed and provided with support and assistance as indicated. Approaching adherence from the standpoint of a health behavior change, similar to dieting or smoking cessation, it should be recognized that people often have several failed attempts prior to successful behavior change. These attempts should not be seen as failures but rather used to help the patient identify how a certain strategy might be changed to enhance future success.
LIST OF REFERENCES


APPENDIX A

RECRUITMENT MATERIALS
WANTED:
HIV Positive Gay Men Who Take Their Meds!

If you are an HIV positive gay man who takes your HIV medication on schedule without missing many doses your help is needed! The purpose of the study is to gather information about how some men on HIV medication are able to be adherent to their medication schedule when others are not. If you have a high level of adherence to your medications and would like to help others you should consider taking part in this study. I am doing this research for my doctoral dissertation in nursing at The Ohio State University.

What is involved?

It would require a time commitment of about 2 ½ hours. You would be asked to fill out a brief questionnaire and then participate in a group discussion with no more than 7 other gay men who perceive themselves as being adherent in taking their HIV medications.

What do you get out of it?

Sharing your knowledge of how to be adherent may help other people who are struggling learn how they too can be adherent and enjoy the health benefits of taking their medication as prescribed. You can leave the study knowing that you might have helped another person with HIV to fight a better battle against their disease. Each person who participates in the group will receive $25 for their time.

Want to find out more about the study?

Call me, John Brion, at 614-261-9034 or e-mail me at jbrion5999@wowway.com

When you call I will be very happy to answer any questions, determine if you are eligible for being in the study, tell you more about the study, and then ask if you are interested and willing to be in the study.
HIV Positive Men needed for Research Project

Many people with HIV have a very difficult time taking their medication when and how it is scheduled. Health Care providers are always trying to find better ways to help people improve their adherence to medication schedules. John Brion, a member of King Avenue and a doctoral student in nursing at Ohio State, is conducting focus group research about adherence to HIV medication in gay men. John is interested in talking to gay men on HIV medication that have a high level of adherence to their HIV medication schedules. Gay men who are very adherent with their HIV medication schedule are needed for this research project. If you (or someone you know) meet these criteria, please consider this opportunity to help other people living with HIV by participating in this project. The focus group interviews will be conducted at King Avenue and will require a total time commitment of about 2.5 hours. Individuals who participate in the study will receive $25 for their time. If you would like more information or are interested in participating in the project please contact John Brion at (614) 261-9034 or jbrion5999@wowway.com.
Thank you for calling. I am conducting research with HIV positive gay men who are doing a very good job taking their HIV medication. I am hoping to learn more about how people are able to be adherent to their medication schedules. I am conducting this study for my doctoral dissertation at The Ohio State University College of Nursing under the supervision of Dr. Edna Menke, a faculty member in the College of Nursing. In order to see if you meet the criteria to participate in this study I need to ask a few questions.

1) Are you an HIV positive gay man who was diagnosed with HIV more than 12 months ago? (If yes continue, if No, say thank you but you do not meet the inclusion criteria for this study). 2) Have you been taking HIV medication for at least 6 months? (If yes continue, if No, say thank you but you do not meet the inclusion criteria for this study). 3) Do you consider yourself to be very adherent to your medication schedule? (If yes continue, if No, say thank you but you do not meet the inclusion criteria for this study). 4) Are you currently employed? (If yes continue, if No, say thank you but you do not meet the inclusion criteria for this study). 5) Are you 25 years of age or older? (If yes continue, if No, say thank you but you do not meet the inclusion criteria for this study).

Great, you meet the criteria to be included in the study.

The study will consist of completing a brief questionnaire and participating in a focus group discussion about your experiences with HIV and taking your medication. The time commitment will be about 2 and a half hours. The group session will be audio-taped. The focus groups will be conducted in a discrete location at King Avenue United Methodist Church. Your information will be confidential and participation is totally voluntary. You would receive $25 even if you begin the study and then withdraw after beginning the study. Do you have any questions about the study? If you want more information about the study you can contact Dr. Edna Menke at menke.3@osu.edu or 614-292-8045.

Are you willing to participate in the study? If you are willing to participate, let me know if you would be able to participate in a research session on one of these dates. This sentence will be omitted --Which of the following dates would work best for you?
Script When Attend Research Session

Hello, my name is John Brion and I am a registered nurse working on my doctorate at the Ohio State College of Nursing. I am working on my doctoral dissertation under the supervision of Dr. Edna Menke a faculty member in the College of Nursing. Thank you for coming as you are interested to be in the study that discussed with you in our telephone conversation. My study focuses on gay men living with HIV and their experiences with taking HIV medication. I am particularly interested in finding out about gay men’s adherence to their medication schedule. The findings of this study are intended to help others learn how they can take their medications more regularly. I would greatly appreciate if you would be willing to participate in my study. It will involve filling out a brief questionnaire then meeting in a group with no more than six other gay men living with HIV to talk about your experiences with HIV and taking your medications. The group session will be audio-taped. The group will last between one and two hours. Do you have any questions about this study? If you want more information about the study you can contact Dr. Edna Menke at menke.3@osu.edu or 614-292-8045. Are you willing to participate in this study? (If the individual agrees to be in the study, then I will explain the consent form and have them sign it prior to conducting the focus group)

You have consented to participate in a focus group and complete a brief questionnaire. Please do not put your name on the questionnaire. You may skip any question you do not want to answer. During the focus group only use your first name or an alias. Also be mindful of what you disclose and treat what you hear as confidential in the group and do not allow it to leave the room after the session is over. You may talk as much or as little as you wish during the focus group, however I would ask that you consider the other members of the group and assure that everyone has enough time to talk. I will help you to focus on the discussion topic if needed and may need to interrupt your comments to ask questions or to assure adequate time for all participants to speak. If you decide at any point that you would like to stop participating you are free to do so and may leave whenever you wish. You are under no obligation to participate in the study. You may ask questions at any time while completing the questionnaire or during the focus groups.

You will receive $25.00 even if you begin the study and then withdraw after starting the study. If you would like to have a summary of the results of the study you may provide your name and address on a separate sheet of paper and I will mail you a report.

Thank you very much for your participation.
APPENDIX B

FOCUS GROUP QUESTIONS
Focus Group Questions

Opening Question

1) Please tell us your first name and how long you have been living with HIV

Transition Questions

2) Share with the group something that you would like us to know about you.

3) When did you first begin taking HIV medications?

Key Questions

4) Think back to when you first began taking medication. What was it like for you to begin taking HIV medication?

5) What is it like now to take HIV medication?

The following are areas that may need to be explored depending on how detailed the questions (3, 4, 5) are answered:

a. What has been helpful in taking your medications as prescribed?

b. Have you found anything to be problematic in taking your medication as prescribed?

c. Share with us about people in your life who play a role in your taking medication

d. Tell us about your relationship with your health care provider
Ending Question

6) In relation to taking medication for HIV, is there anything we should have talked about but didn’t?
APPENDIX C

BACKGROUND INFORMATION FORM
Perspectives Regarding Adherence to Prescribed Treatment:
A Focus Group of HIV Positive Men
Background Information Form

Fill in the blank or check the response that best fits you as an individual

How old are you today? _______ (state in years)

Race:
___African-American
___Caucasian
___ Hispanic
___ Asian
___ Other (describe ______________________________)

Partnership status:
___Single
___Partnered

Living arrangement:
___ live alone
___ live with partner/spouse
___ live with roommate (how many ____)
___ live with parents
___ other (explain___________________________________)
What is your yearly income?
___ no income
___ $1 - $25,000
___ $25,001 - $50,000
___ $50,001 - $75,000
___ $75,001 - $100,000
___ $100,001+

What is your yearly household income?
___ no income
___ $1 - $25,000
___ $25,001 - $50,000
___ $50,001 - $75,000
___ $75,001 - $100,000
___ $100,001+

Alcohol use?
___ none
___ one or two times a year
___ one or two times a month
___ one or two times a week
___ daily (how many drinks on an average day? ___)

Recreational (street/party) drug use?
___ none
___ one or two times a year
___ one or two times a month
___ one or two times a week
___ daily

If you do use recreational (street/party) drugs, what kinds have you used in the past 6 months? _____________________________

In what year were you first diagnosed with HIV? ____________
How long ago did you begin to take medication for your HIV?

What medications have you taken for your HIV (please list all you can recall).

What drugs are you currently taking for your HIV?

How many pills do you currently take each day for your HIV or other health problems?

How many times do you have to take pills each day?

Have you ever had any health problems related to your HIV? (explain/list)

Have you ever been in the hospital for HIV-related problems?

What is your current viral load? (approximate)

What was your highest viral load? (approximate)
What is your current CD4 count? (approximate)

What was your lowest CD4 count? (approximate)

How many scheduled doses of medication have you missed in the past three days (72 hours)?

How many scheduled doses of medication have you missed in the past two days (48 hours)?

How many scheduled doses of medication have you missed in the past day (24 hours)?