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Factors Influencing Medical Adherence of Clients in AIDS Project Worcester

Marianne M. Sarkis
Clark University, msarkis@clarku.edu

Abby Dnahue
Clark University

Jacqueline Osei-Owusu
Clark University

Shan Yi Koay
Clark University

Maya Baum
Clark University

See next page for additional authors

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Authors

Marianne M. Sarkis, Abby Dnahue, Jacqueline Osei-Owusu, Shan Yi Koay, Maya Baum, Anna Shayo, and Amanda Major

Research Report: Factors Influencing Medical Adherence of Clients in Aids Project Worcester (APW)

Written By: Abby Donahue, Jacqueline Osei-Owusu, Shan Yi Koay, Maya Baum, Anna Shayo, Amanda Major

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Professors Ellen Foley, Marianne Sarkis, Barbara Goldoftas

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ABSTRACT

Over the last few decades, the HIV/AIDS epidemic has undergone a visible shift. In particular, the demographics of HIV/AIDS infected persons have transitioned from mostly gay affluent, white males to women and men of various minority populations with lower resources and socioeconomic statuses. This trend has also been true for the Worcester community. Based in Worcester, Massachusetts, this research project seeks to identify patterns between the recent change in client demographics and the relation between client adherence at AIDS Project Worcester (APW). A group of student researchers from Clark University examined the barriers to complete adherence within HIV positive clients at APW. Qualitative research within APW revealed that self-efficacy combined with the ability and knowledge to navigate the mechanics of the health care system are the necessary antidote for clients to achieve 100% adherence.

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Conceptual Framework:

In exploring medical adherence of clients who receive case support through AIDS Project Worcester (APW) in Worcester, MA, a non-profit organization that serves the HIV/AIDS community in the city by providing both educational and health services to infected individuals and families, our goal is to discover and expose factors that may support or impede medical adherence for clients. Under APW clinical definitions, medical adherence is completely and correctly following medication regimens as well as regularly attending case manager meetings and doctor appointments. This research aims to assist AIDS Project Worcester in adapting their services to better meet the needs of clients in reaching medical adherence.

The national priority in HIV/AIDS care is to improve medical adherence among patients. Furthermore, the Boston Public Health Commission (BPHC) and Department of Public Health (DPH) are APW's two main funding sources and are increasing pressure on APW to ensure their clients are adhering to their medical treatment. The funders and APW are attempting to gain an understanding of why people are or are not adherent to their medical treatment. Complete medical adherence according to APW includes the strict maintenance or regular attendance of doctors' appointments, following doctors' orders, and following prescribed medication regimens without missing a single dose. Currently, there has been no research conducted on client adherence at APW and a large "fuzzy middle" group remains the majority. This "fuzzy middle" group includes all clients that are not medically adherent according to this definition. APW understands that there are clients who are completely non-adherent and out of care. While APW keeps these clients in their case management system, they are not a population that was studied in this research. Additionally, APW's funders are constantly trying to encourage clients to increase their connection to medical care and would like to explore barriers that may hinder access to such resources. For these reasons, APW has invited us to conduct a study to help better understand client medical adherence.

The literature review provided insight on our population demographic as well as barriers or challenges towards 100% medical adherence for HIV infected persons. This study defines complete medical adherence as completely and correctly following medication regimens as well as regularly attending case manager meetings and appointments. After a review of the literature regarding medical adherence in the case of HIV/AIDS, we determined that there are five major categories that effect adherence. These categories include social and economic barriers, health care system dimension, patient-related dimension, therapy related dimension, and the condition related factors.

HIV/AIDS patients face multiple social and economic barriers that limit their capability for complete medical adherence. Social factors such as a lack of social support network, and low health literacy become significant barriers when patients need to take medication in an appropriate time frame (Kalichman et al. 2001;Gonzalez et al. 2004)). Economic factors such as unstable living conditions/homelessness, lack of health care insurance/limited access to health care facilities, and medication costs are also debilitating factors on the road of complete medical adherence (Carballo et al. 2004).

According to Dimatteo (2002), adherence is a factor in the outcome of medical treatment, but the strength and moderators of the adherence-outcome association have not been systematically assessed. (Giordani et al.2002). Therapy related factors that can influence adherence or non-adherence to medication could be categorized as complexity of medication regimen (number of daily doses; number of concurrent medications), treatment requires mastery

of certain techniques (injections, inhalers), duration of therapy, frequent changes in medication regimen, lack of immediate benefit of therapy, medications with social stigma attached to use, actual or perceived unpleasant side effects, and treatment interferes with lifestyle or requires significant behavioral changes (World Health Organization, 2003). Based on existing research findings, some of these themes will be discussed in this section to reflect how they are actually in effect in the case of HIV/AIDS.

Functioning within the structure of the health care system is another key factor of adherence. Personalized care within the healthcare system for most HIV/AIDS positive patients includes regularly scheduled doctors' visits and prescription medication. Alternative care approaches within this system may involve cognitive behavioral programs or at-home components such as home visits or self-monitoring of care. Regardless of what the specialized care may include the efforts work towards achieving maximum patient health through medication compliance. Standardized treatment of HIV/AIDS patients within the institution of biomedicine is led by prescription medication adherence. This factor lies at the forefront of disease adherence, and cannot function without the structures of the health care system.

Patient-related factors are integral to creating a holistic understanding of adherence levels concerning HIV drug regimens. Several different factors are tied directly into patient-related issues such as stigma, substance abuse, and perceptions of service provision (provider or case manager). These factors influence patients' perceptions of medical care and adherence. Oftentimes, patient-related factors, or behavioral factors, are viewed as issues that patients have direct influence and control over. However, external environmental factors influence patient-related factors as well. Factors influencing medical adherence of patients are intersectional and interdependent.

The knowledge base created by the literature review, allowed the researchers to conduct four informal case manager interviews, three formal client interviews and one interactive focus group. This approach revealed client-participant experiences and their direct and indirect effects on medical adherence.

THE STUDY

This research utilized a combination of both primary and secondary research and used a mixed methods approach. The site of our primary research was AIDS Project Worcester and the data was collected through interactions with clients, case managers, and peer advisors. Peer advisors are individuals who have been diagnosed as HIV positive that provide social support for clients at APW. The timeframe of this research was February 2013 - May 2013.

Laura Krajewski, a case manager at APW, was our initial contact with the organization and remained in contact with us throughout the research process. Through our discussions with her, we were able to gain a better understanding of APW, their mission, and their needs. It was this initial contact, primarily early email exchanges and on-site meetings within the first two weeks, that led us to conclude our work would best serve the needs of APW by researching factors that impede or support client medical adherence.

To gain background knowledge on the issue, we conducted an in-depth literature review that gave us working theories on the factors that can impede or support medical adherence among persons living with HIV or AIDS. As previously discussed, we organized the literature into five sections that represented the five main theories we would base our research on. In addition to researching the different theories surrounding medical compliance, we conducted a literature review about APW and HIV/AIDS in Worcester.

Once our research design was completed and approved, we began our data collection. To begin, we met with four case managers at APW and had informal conversations with them. The goal of these conversations was to find out what their theories were regarding adherence with their clients, and then to compare their theories with the theories from the literature as well as the data from client interviews and the focus group. During this same period of time we visited the agency to review client charts. We reviewed a total of 50 randomly selected charts and created a spreadsheet with the different questions to organize this data. This review was planned to gather data from APW's new adherence questionnaire that we had been informed case managers were beginning to use. However, we found that the charts had very limited information on adherence itself. Because of this, the data we collected did not speak much to client adherence, and instead we primarily used the information as an insight on the demographics and backgrounds of the clientele.

Once all our background data and information was gathered, we began to conduct formal interviews. Based on the advice from Laura and the other case managers, it was decided that the best way to find clients to interview would be to come into the agency on Tuesdays. On Tuesdays, APW opens their food bank and clients come in and choose the food they want to take and on the first Tuesday of every month APW gives out transportation vouchers. This is the time when the agency is busiest as a large percentage of APW's clientele come to take advantage of these resources. During this time we were able to conduct three formal interviews with clients, asking them a set of questions including information about their daily medical routine (i.e., daily prescription intake, doctors' appointments, and/or case management sessions).

An interactive focus group was also conducted through a regular support group held every week at the agency. The focus group was held for one hour and utilized an interactive format so that the eight garnered participants could speak freely about their challenges and successes with medical adherence. Three of the researchers attended the focus group in order to record, take notes, proctor the discussion, and interact with participants. The first task during this session was to explain our research, confidentiality, and to receive consent. Participants were then given large pieces of poster paper and markers in order to jot down their barriers towards medical adherence. Afterwards, participants were given ten star stickers to place on what they thought were the most challenging barriers on their papers. The second section of the focus group was interactive in the sense that participants were given a chance to share and discuss what they wrote on their papers. The discussion was kept casual and participation was on a volunteer basis. Participants were encouraged to speak freely among themselves with minimal questions from the three researchers.

With the consent of all participants during the formal interviews and focus group, we used a tape recorder. All the interviews and the focus group were transcribed and saved on our group's Dropbox folder. Backups were made and put on an external hard drive.

Data Analysis

Software

For the data analysis process, we manually organized our data using Microsoft Word 2007 and Microsoft Excel 2007. Due to the small size of our research sample, our preference was to code manually as opposed to using software such as Atlas.ti or SPSS.

Procedure

Coding was the first step in the analysis process. To begin, an Excel spreadsheet was organized into two tabs: “Original codes” and “Categories”. Each tab consisted of two columns: one for the code, and another for the frequency of the code. Using “insert comment” in Microsoft word, we began to manually code the interview transcripts and focus group transcripts line-by-line.

Simultaneously, each code was manually entered and organized into the Excel spreadsheet. The “Original codes” tab consisted of all the codes identified in our focus group and interview transcripts. The “Categories” tab consisted of collapsed codes from the first tab, organized into headings under which individual codes were placed. For example, “Medication Issues” was a heading under which codes relating to the difficulty in taking medication were organized such as pill size (See Annex III). Categories were generated based on assessing codes and identifying salient themes, recurring ideas, and patterns. The codes in the “Categories” tab were arranged from highest to lowest frequencies and then collapsed further into ten categories. A draft code book was then created consisting of all the codes in the “Categories” tab and their definitions. The definitions of the codes were determined based on their relevance to the research question.

STUDY LIMITATIONS

This study had some limitations related to our methodology, instruments, population, and study design in general. The sample size was smaller than planned due to time constraints. We could have included more participants if we had started collecting earlier or extended the time period. It was difficult meeting clients because we had to piggyback on APW activities like food bank and support group meetings to be able to access and identify participants. Recruiting participants and conducting interviews as well as a focus group discussion on APW premises could have influenced participant’s responses. We also had a challenge with language due to the fact that many clients spoke English as a second language, or not at all. A large Hispanic population proved to be a barrier as, it is possible that they could have better expressed themselves in their native languages, but none of the research team members speak Spanish. We had to do our best to communicate comprehensively in English to minimize the effects of the language barrier. Charts review was very challenging because the sampled ‘Needs Assessment’ forms did not have a standard format. This made it difficult to gather consistent data from this tool, and resulted in minimal findings on adherence.

RESULTS

Our study population consisted of clients from AIDS Project Worcester (APW) in Worcester, Massachusetts. A total of sixteen clients participated in the study. As mentioned in our methodology, we also reviewed fifty client charts to collect general demographic data on APW clients.

The from the charts we can illustrate a sample of APW’s population demographic in terms of gender (Figure 1), marital status (Figure 2), income (Figure 3), employment (Figure 4), and housing (Figure 5). Initially we had hoped that these charts would provide us with clients’ medical adherence information, but as has been discussed this information was inadequate. Instead we were able to use the data in gathering these demographics. By looking at APW demographics we are provided with a better understanding of APW’s client needs and can begin

to formulate our theory by relating these needs to self-efficacy and the logistics/mechanics of the healthcare system.

Figure 1: Gender Sample

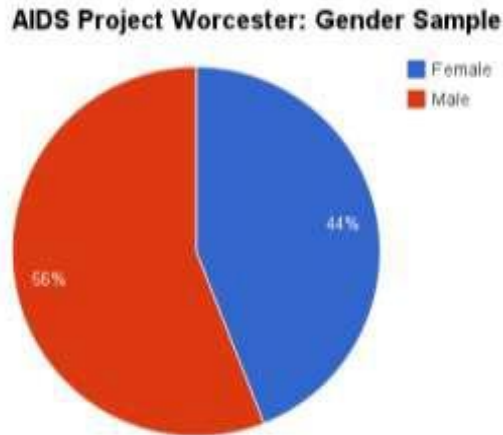


Figure 2: Marital Status Sample:

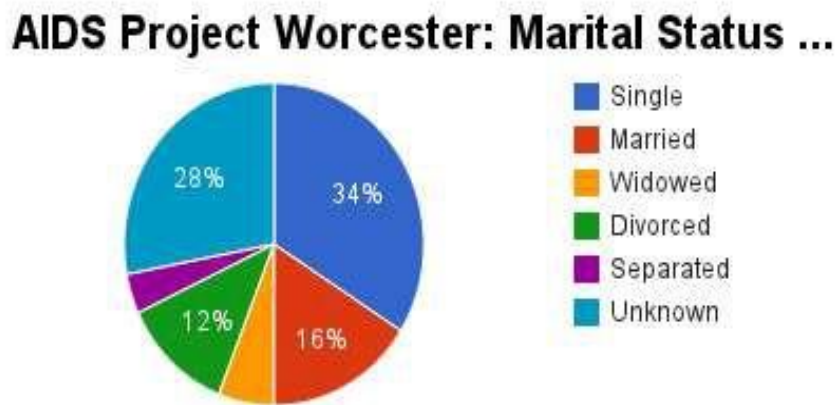


Figure 3: Income Sample

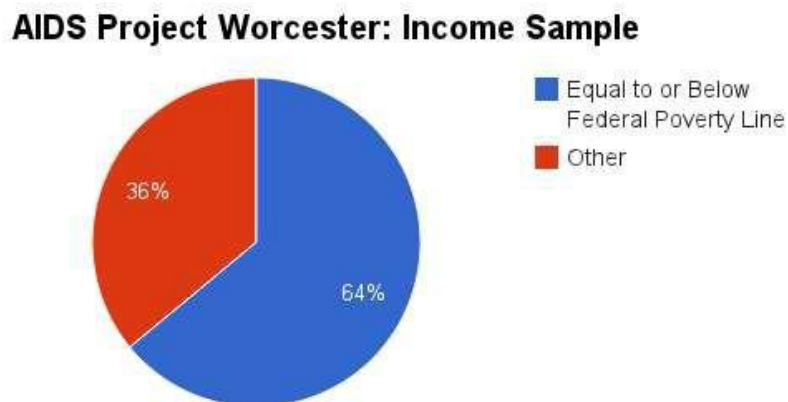


Figure 4: Employment Sample:

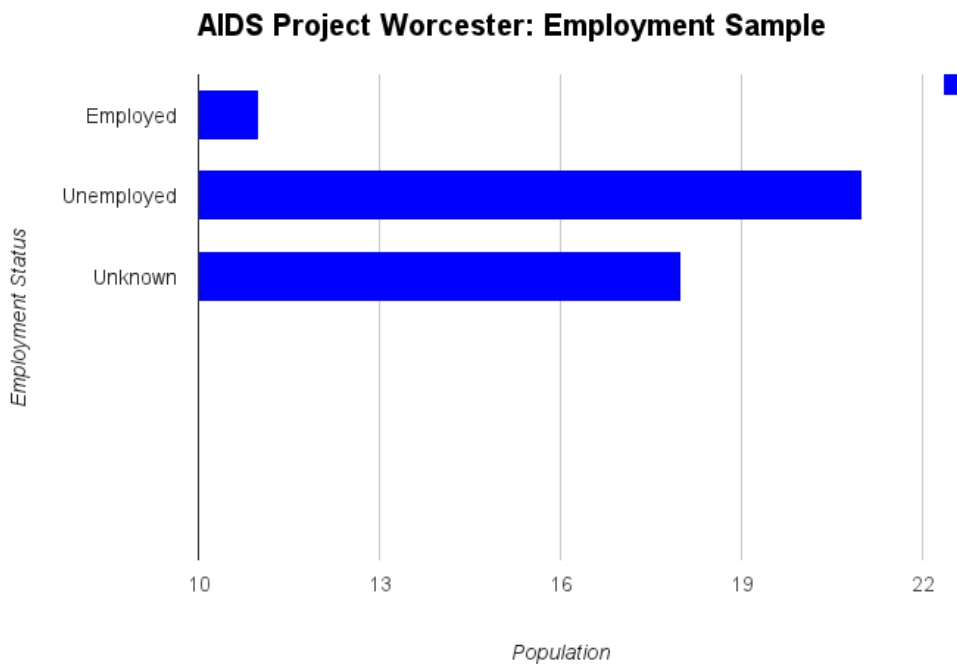
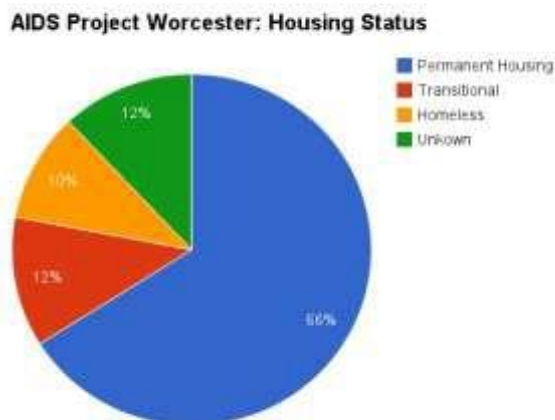


Figure 5: Housing Sample:



APW currently provides services to about 513 individuals living with HIV/AIDS and about 1,529 affected individuals. The purpose of the population sample charts above is to provide a more narrowed assessment of the general population. Figure 1 for gender of the random population sample data illustrates that 56% and 44% of the sample were male and female, respectively. Figure 2 for marital status indicates that 34% are single, 16% are married, 6% are widowed, 12% are divorced, and 4% are separated. The income sample in Figure 3 shows that 64% of this population is equal to or below federal poverty line. Figure 4 shows that 22% are employed, and 42% are unemployed. Additionally, Figure 5 illustrates that of the sampled population, 65% have stable housing, 12% have transitional, and 10% are homeless. These

statistics exemplify the low resource and poverty background of APW’s client base; furthermore, they give light to the changing demographics of the HIV/AIDS clientele. Uncontrollable aspects such as marital status, low income, unemployment and unstable housing conditions are root causes of hardship in the journey for high self-efficacy and understanding of the healthcare system.

Following data collection and analysis from our interview and focus groups, we developed ten super categories. These were: Medication Issues, Health Provider Issues, Social Factors, Stress, Mental Health, Transportation, Discrimination Towards HIV Infected Persons, Disclosure, Drug Addiction, and APW Issues (refer to the code book in Annex 4 for a full definition of each category). Listed below are the final categories and their frequencies:

Table 1: Final Categories and Frequencies

| Category | Frequency |
|---|------------------|
| Medication Issues | 76 |
| Health Care Provider Issues | 60 |
| Social Factors | 42 |
| Stress | 35 |
| Mental Health | 35 |
| Transportation | 27 |
| Discrimination Towards HIV Infected Persons | 27 |
| Disclosure | 18 |
| Drug Addiction | 14 |
| APW Issues | 7 |

After thorough analysis of the final codes, we were able to identify two main themes: Self-efficacy and Logistics/Mechanisms to the Health Care System. These are explained in further detail below:

Self-efficacy: In the context of this study, we have defined self-efficacy as an individual’s ability to make decisions, complete tasks, and reach goals. Self-efficacy is key to a client’s adherence. Clients with a higher self-efficacy are more likely to be adherent because they are better equipped to navigate the necessary components of the system and have the knowledge and motivation to utilize these resources.

Logistics/Mechanics to the Health Care System: For the purpose of this research we defined the logistics/mechanics as the necessary nuts and bolts of the healthcare system that clients must have access to in order to be adherent. This includes transportation to doctors' appointments, insurance, access to medication, and counseling.

Theory: In order to be 100% compliant, clients must have *both* high self-efficacy coupled with the ability and knowledge to access health care and support systems.

Discussion:

A major finding in our literature review was that HIV/AIDS patients face multiple social and economic barriers that limit their capability for complete medical adherence. Our study findings strongly confirmed this finding as the main conclusion of this study suggest that for clients to be 100% compliant they must have both high self-efficacy and the knowledge to navigate the logistics/mechanics of the healthcare system. The results of this study suggest that the level of of AIDS Project Worcester (APW)'s clients' self-efficacy has been fluctuating over the years. This can be partially attributed to the trajectory transition of clients' demographics from a predominantly wealthy white males in the 1980's to the now increasingly diverse population majority of whom are women and men of color with a background of poverty and low resources. Furthermore, results demonstrate that clients have a low understanding and limited access to the logistics/mechanics of the healthcare system. In the case of APW, these two factors impede 100% client medical adherence.

Literature review findings reveal that barriers to medical adherence lie in social and economic barriers, access to the healthcare system, patient-related dimensions, and condition-related factors. These were evident in our interviews, focus group and population sample chart data. Interviews and focus group data showed that factors for medical adherence that had a high frequency in coding indicate low self-efficacy, low understanding, and limited access to the health care system. Factors with high frequency that generated low self-efficacy were stress, social factors that emanate from an individual's social environment, mental health barriers, drug addiction, discrimination towards an individual that is HIV+ and disclosure. Factors with high frequency that formed barriers to a client's understanding and access of the health care system, included issues with transportation, APW support, health insurance, healthcare provider problems, and medication issues. These barrier factors are intensified with poverty and limited resources. The following paragraphs will examine these findings in greater detail.

High Frequency Factors for Self-Efficacy and Medical Adherence

Among participants, stress garnered the highest frequency at 30. This study suggests that stress is a barrier for high self-efficacy, and in turn 100% medical adherence. Social and economic factors that cause clients to feel stressed and experience other negative emotions may impede their ability or motivation for adherence. Participants in both the interviews and focus group were stressed due to various reasons. However, across all clients, stress impacted how they felt, and ultimately their self-efficacy and adherence. For example when asked to describe what the barriers they faced to medical adherence, participant 7 of the focus group stated "...besides having HIV I have Crohn's disease and I always have to go the hospital...". This alludes to the fact that the participant feels stressed from frequent visits to the hospital due to having multiple

diseases. The participant continued to explain other types of stress in his life "...quality of life kind of sucks sometimes so it's stressful because you can't achieve the things you want to achieve...health holds you back and that can be stressful". The participant analyzes both diseases as stressful and as a barrier to life accomplishments. Stress from the disease and its barriers have a negative impact on the participant's emotions. This distorts the ability to make decisions, complete tasks, and reach goals. This in turn constructs low self-efficacy and ultimately, low adherence levels.

The interviews and the focus group further revealed that social factors could impact self-efficacy rates. For the purpose of this study, we have defined social factors as factors that emanate from one's social environment including family, friends, and other relations that either help or impede adherence to medication. This includes cultural beliefs, religion, homelessness, stigma and so forth. Participant 2 of the focus group shared that a close friend stayed with her for a recent hospital stay. She stated that during a particularly hard time when she was denied smoking a cigarette by hospital staff, her friend was there "...I was like holding her crying hysterically and obviously that wasn't just about a cigarette you know". While the participant's behavior of smoking a cigarette could impede total medical adherence, social support from a close friend helped her, for a short time, to adhere to hospital rules which could directly help her adhere to medications.

Participants also rely on religion and awareness for help with adherence. An interview participant stated that "as long as I'm doing the right thing, like keep my faith in the Lord, talk to others about the reality of the disease it can be controlled". This participant uses religion to help them with medical adherence as well as to spread awareness about their disease. High self-efficacy is exemplified through this participant because of the ability to make positive decisions in the context of the disease; this fosters medical adherence as well.

Another interviewed client demonstrated medical adherence through the support from their family, "...my daughter is around, my brother gives me rides...see a lot of people have counselors, see I don't need no counselor, I got a whole bunch of family, I talk to my family and friends". In this case, the participant's family acts a resource for support in making decisions, completing tasks, and reaching goals. This results in higher self-efficacy and facilitates an environment of medical adherence.

Homelessness is a social factor that impedes medical adherence. Figure 5 shows that 10% of the sample population is homeless and 12% have transitional housing. An unpredictable housing status can impede a client's medical adherence because of the added stress and pressure. Participant number 4 of the focus group spoke about the challenges that arise from both homeless and HIV+. She states "...I was homeless at one point and the last thing I thought about was going to a medical appointment or taking medication...where could I put my meds?! If they needed to be refrigerated, I did not have a fridge...". Although homelessness can be a product of uncontrollable circumstances (such as unemployment or lack of a support system), added stress and pressure that arises from this situation can lead to the participant's inability to make sound decisions regarding her health, and ultimately trumped medical adherence practices.

Within this population, our research has found that the stigma of being HIV positive is another social factor that impedes medical adherence and hinders patients from receiving effective care. All study participants felt that stigma of HIV/AIDS was a barrier for 100% medical adherence. For example, a participant stated that "...being stigmatized right there in the healthcare facility is reason why someone may not stay engaged in care or go to see a medical provider...". The negative stigma related to HIV/AIDS leaves clients with subpar care in

hospitals and other healthcare facilities. Research has also shown that a patient's attitude towards their healthcare provider is a key factor in creating effective visits (Chesney, 2000). Stigmatization from healthcare providers creates a negative space for the client and results in low self-efficacy because of lack of access to key resources for medical adherence and HIV/AIDS.

The mental health of a person can either help or impede self-efficacy and medical adherence. It relates to the mental state of clients, positive or negative, including mental health diseases, positive attitudes, seeking mental health care, negative emotions, depression, denial and so forth. A 2010 study conducted by Singh et al found that patients, who were non-compliant, demonstrated depression, psychological distress, emotional disturbance and poor adaptive coping. Participants of the study embodied mental health issues in relation to HIV/AIDS. A participant stated that medication side effects for herself included "...puking, nightmares, sleep, discomfort, mental problems and it affects me wanting to take the pills or not wanting them or feeling like medicine isn't really helpful..." A side effect of the prescribed medication is mental problems, which makes the participant feel as though she does not want to continue taking the medication and creates a negative attitude as well as non-compliance. The side effects lower her ability to make decisions (self-efficacy) towards medical adherence. Another participant stated, "...mental health issue plays a major part of someone staying in care and I know for me, mental health... I used to think of that and I thought I was crazy but no, it's just having an outlet to go and talk...there is nothing wrong with talking about your issues, so your issues does not have to be everybody else's issues". This participant struggled with how to deal with mental health issues until he found an outlet through therapy. In the beginning he perceived himself to be "crazy", but throughout time he realized that he would be better served in therapy. The participant's story is characterized as having low self-efficacy in the beginning however, utilizing resources and seeking professional help raised his self-efficacy and potential for medical adherence.

Within mental health, a positive attitude can also help with medical adherence. Participants who experience negative emotions/attitudes due to having the virus have in turn had negative experiences. A client who participated in an interview showed notable positive attitude that has helped her with living with the virus when she said "...so I really don't let people bother me anymore, actually I turn the tables around and make a joke out of you instead of joking about me, but I don't let things like that bother me anymore". She goes on to say that when taking medication she has come up with an interactive method that makes her grand children enjoy the process as well. The participant specifies that when taking medication "no matter what I take it with I still burp, my grandkids think that's funny but that's how my kids know that I take it, they hear me burp and they know 'yea she took it'". The burping method is not only interactive and fun for the children; it also fosters the idea of a community and support system within the household that helps her with medical adherence. The attitude of letting comments go, sticking to a positive outlook and interactive medicine taking methods, seems to counteract the negative emotions/attitudes that can arise from living with HIV/AIDS. They construct the idea of a support system and positive mental health showing high self-efficacy as well as medical adherence.

On the other hand drug addiction can negatively affect one's self-efficacy and impede medical adherence. This applies to clients who have difficulty being adherent due to their status as past and/or present substance abusers. It includes missing doses or doctors' appointments due to a drug-induced state of mind, taking drugs instead of medication, abusing prescription drugs and so forth. While these issues are normally viewed to be in the client's control, external

environmental factors can also influence substance abuse. During client-participant interviews the issue of substance abuse did not come up, however, the focus group discussion revealed that substance abuse has been an issue for clients at APW. Participant number 2, previously mentioned for having a support system during a recent hospital stay for the diagnosis of MRSA in conjunction with AIDS, declared that drug addiction is an issue for her. During her hospital stay she was “feigning for a cigarette” and against hospital staff wishes “...I did sneak into the bathroom and took two drags...”. During this time hospital nurses had offered her the Nicorette gum in order to reduce cravings. While the “craving went away” her addiction still overwhelmed her. The presence of an addiction in her life causes her to disregard medical care provider orders, and make poor decisions for health.

Another focus group participant discussed past drug addiction as a barrier to her medical adherence. At this point she is a recovering drug addict however looking to the past she recalls that “...I know I put my HIV meds or drugs down to pick up the illegal drugs” in general she feels that drug addiction “...plays a major part in why someone won’t go to appointments, adhere to their medication or stay engaged in care”. Her sentiments apply to the previous participant’s challenges with drug addiction in regards to adhering to medication and staying engaged in care. Substance abuse impedes an individual’s ability to adhere to medication because it cultivates low self-efficacy patterns in behavior. The first participant showed struggle overcoming an addiction in a hospital setting while the second participant shows knowledge gained from educational resources on the negative effects of substance abuse on HIV/AIDS medical adherence. Through its client and prevention services, AIDS Project Worcester helps its client base with substance abuse however, ultimately it is the decision of the individual to stop substance abuse and recover from drug addiction with the resources that AIDS Project Worcester offers.

AIDS Project Worcester also aims to enhance the lives of individuals who face HIV/AIDS stigma and discrimination. Previously the idea of stigma bore negative effects on a client’s medical adherence; discrimination against individuals HIV/AIDS status also created negative effects for the client. Discrimination is the awareness of subtle differences and the display of negative actions/inactions from society because of these differences. In the American society these actions/inactions are mainly caused by fear and lack of knowledge surrounding the disease. The poor treatment of the individual results in poor medical adherence practices because of negative feelings that are felt by the client. Participants of this study voiced that the negative treatment they have encountered from primary medical care providers, and pharmacies have impacted their adherence levels in terms of going to the hospital, and picking up medication. Participant 2 of the focus group feels that when she goes to her primary care doctor, she receives subpar treatment. She states “I’m not treated with respect, I know they look down on me and my case manager has come with me before and has seen how they treat me... my doctor is like big time anti drugs and it was very hard for me to get honest with him”. Formerly, this participant identified drug addiction as a pressing issue in her life. The discrimination she faces at her primary care doctor suppresses her needs for help as a substance abuser and as a person living with AIDS. In turn she does not receive the proper tools and resources that encourage medical adherence and self-efficacy. She is not only left to feel alone in her journey, she also cannot properly access medical care or knowledge about AIDS. Sharing the sentiment of discrimination, another participant stated that pharmacies are “...very discriminatory towards people with HIV because they know what meds are for HIV so when they give you the bag, sometimes, they have a little attitude towards you, it happened to me a month ago”. The indirect actions of

discrimination caused by lack of knowledge of the disease caused the participant to feel uncomfortable. These negative emotions could later result in the participant's poor decision of not getting her medication, which would lead to non-medical adherence. The fourth participant shared a story of a time when she went for a doctor's appointment. The doctor opened the door and stated "you're a pain in my ass" then closed the door. The participant proceeded to ask if that was directed towards her and to her surprise the doctor indicated it was. The patient addressed the situation by telling the doctor that she will not tolerate that type of behavior. The participant's actions against discrimination indicate self-efficacy.

Discrimination against an individual that is HIV+ leads to the final issue of disclosure that fosters low self-efficacy as well as non-medical adherence. This study defines disclosure as the clients' level of comfort in storing and taking their HIV/AIDS medication around others (family, friends, public, and strangers). This can affect an individual's ability to take their medication due to shame, fear and/or embarrassment. It includes not taking medication due to too many people around, keeping their HIV status private from family and friends and so forth. However, it can also include clients whose family and friends are aware of their status and thus do not feel the need to hide their medication. Disclosure can help or impede medical adherence. Participant 4 of the focus group stated that in regards to disclosure her main challenge has been with denial "...at one point I was in denial and if I am in denial, why the heck would I take medication or why would I even go to an appointment when there is nothing wrong with me?" Her fear of disclosure to those around her nurtured the idea of denial about having the HIV virus. It affected her medical adherence because through this denial she was no longer taking her HIV/AIDS medication or going to doctor appointments. Denial then negatively impacted her decision-making abilities for proper health care and reduced her medical adherence.

Two participants spoke about disclosure in terms of the level of comfort they have with storing and taking their HIV/AIDS medication around family, friends and strangers. The first participant brought up the fact that if he were to take the HIV/AIDS medication that needs to be stored in a refrigerator it would affect his level of comfort with disclosing his status with guests in his house. The participant felt that "...one of the big things in my house is...I don't want people coming to my house knowing that when they go to the fridge to grab a bottle of soda to see the Excentris and think that I am HIV+, there goes your disclosure too". The other participant agreed with thoughts on disclosure relating it to a potential experience she might have with her children's friends. She shares that she also does not want to have HIV/AIDS medication that can be in fridge because of her children's friends. While her children are aware of her HIV+ status their friends are not. She switched from medication that has to be refrigerated to non-refrigerated medication in order to avoid an uncomfortable situation where her children have to explain her status to their friends. The participants' fear of having a certain type of HIV/AIDS medication because of potential discrimination and lack of disclosure can hinder him from 100% medical adherence. If taking a specific medication creates fear and discomfort then the client will be less likely to take the medication for better health and treatment of the HIV virus.

High Frequency factors of Logistics/Mechanics for the Healthcare System and Medical Adherence

This study found that in order for AIDS Project Worcester clients to achieve 100% medical adherence they not only needed self-efficacy but access to the necessary nuts and bolts of the healthcare system as well. Nuts and bolts included transportation to doctor's appointments,

APW issues, healthcare provider, and medication. Access or lack of access to these elements helped or impeded medical adherence among clients.

Transportation is a barrier factor to client medical adherence at AIDS Project Worcester. This study defines transportation as a means used by a client to get from where they reside to their needs service location. Means of transportation include cars, bus, and taxi cabs. This is a necessary component to adherence that clients face difficulties with. It includes issues with transportation vouchers, distance to the doctor or pharmacy, cost of transportation, lack of transportation and so forth. APW offers transportation services in the form of cab vouchers through an application process, which the client-participants of the study found to be an inefficient way to get to and from medical appointments. Participant 1 of the focus group stated that while she drives her own car transportation is still a problem for her. Often times she feels that she "...either has to get a taxi or a voucher or get some kind of help to get to the doctors...". This instability could cause her to miss crucial doctor appointments that would better help her with her diagnosis. Participant 7's issues were that he doesn't receive enough cab vouchers. He stated that "its crazy but what I want to know is why you get 3 cab vouchers and you often have 5 appointments and you gonna decide what you can or cannot use...". Receiving 3 cab vouchers makes the client feel that he has to pick and choose between which appointments to go to while all appointments are crucial to attend. He further states that when he finds himself in this situation he asks himself "...what do I do walk to the appointment and take a cab back home or take a cab and walk home...". This is not an ideal situation for an individual with an HIV+ diagnosis. It causes added stress to the situation and causes further non-medical adherence.

Clients are also eligible for transportation help if they are patients at certain health facilities. Often this option does not work for the client because it is for a specific demographic who go to specific health care facilities. Participant 4 shared that if you "...go to a certain health facility you are not eligible to get transportation vouchers however you can complete a PT1 form but that's a process...". The process to receive transportation vouchers can often be long and during times that clients have doctor appointments. Lack of access to proper transportation is a barrier to medical adherence for some APW clients.

APW has taken strides to offer client services that aid in medical adherence such as transportation, medical care, counseling etc. An interviewed participant stated that APW has helped him with housing through a case manager and another stated that at one point APW even paid his rent for a particular month that he couldn't pay for. However, our research shows that while these programs are generally effective there are some internal issues with the organization in regard to these services. This study defines AIDS Project Worcester issues as internal issues within the organization that make it harder for clients to be adherent. This includes client-case manager interaction/relationships, higher-level management and so forth. When discussing about transportation in the focus group, participants voiced that the issue lies within management. A participant stated that he feels the issue with transportation goes back to funding and allocation of funds. He further stated that he felt that the transportation system for the agency should be "abolished" because of clients selling unused vouchers to cab drivers or using them for other needs other than medical appointments. He further suggests that a system of picking a client at their household and to take them to their appointment whenever necessary. This would in turn reduce cab voucher fraud and abuse.

In conjunction with internal issues at APW, clients also deal with health care provider issues in terms of proper access to the healthcare system. Our research defines health care provider issues as challenges encountered in accessing services from healthcare facilities,

professionals and policies. This includes having too many appointments, dealing with doctors, pharmacies, nurses, care workers, insurance and so forth. Previously, one read the challenges faced by participants with discrimination in a healthcare facility. However barriers towards 100% medical adherence go beyond that for clients. Participant 2 of the focus group further stated that she faces difficulty with not only discrimination at the hospital but also with pharmacies in regards to receiving timely prescriptions. She states that in the past she has a hard time getting on time prescriptions at CVS because they would not accept her HDAP insurance. While HDAP insurance can only be used at one pharmacy for discounted prescriptions, she had no previous understanding of this. Participant 2 also has issues with keeping appointments. She admits that's "sometimes there are so many appointments that I'll cheat and miss a couple". For this participant the issues she faces with discrimination, insurance and lack of attendance for appointments paints the picture that she does not have the necessary nuts and bolts of the healthcare system or self-efficacy. This illustrates that she does not have 100% medical adherence.

Other participants have figured out ways around insurance issues in terms of getting prescriptions in a timely manner. An interviewed participant stated that he applies for other programs that help with co-pays for prescriptions so that "even if my insurance gets mixed up there's a couple of other programs that'll pay my medication until my insurance gets better...". Sharing this sentiment another interviewed participant shared that he relies on the ALLcare pharmacy at AIDS Project Worcester because "...with these people, you don't run out of medication...they deliver them to my house...I take them every day". These two client participants have found alternatives to pay for prescriptions so that they are able to take their medication daily. This shows access to medication and proper insurance that helps them adhere.

Lastly, a factor touched upon in disclosure and self-efficacy is medication issues. This study defines medication issues as reasons for not adhering to medication; problems that APW clients face in taking medication and adhering to their medication regimes. These include side effects, having too many pills, oversleeping, and having to refrigerate pills and so forth. In disclosure and self-efficacy our study found that a reason for lack of medical adherence for two participants was refrigerating HIV/AIDS pills and fear of others discovering them. Our study also found that participant 5 of the focus group had problems taking medication because of side effects which included "...puking, nightmares, sleep, discomfort... affecting wanting to take the pills or not wanting to take them...". Side effects are a medication issue because they influence decisions of medical adherence. Participant 7 of the focus group also stated with taking medication the biggest issue is "...oversleeping because I turn the alarm off and I sleep later and later then end up not getting up until 10 o'clock when I was supposed to take my meds at 9 o'clock...". Medication issues have proven to be a negative impact on medical adherence.

Self-efficacy and understanding the necessary logistics/mechanics of the healthcare system are factors that can help or impede medical adherence for clients at AIDS Project Worcester. Factors within self-efficacy and the logistics/mechanics of the healthcare system included stress, social factors, and discrimination towards an individual who is HIV+, mental health issues, drug addiction, disclosure, transportation, APW issues, health care provider issues, and medication issues. All of these factors affected our client-participants in both the interviews and focus groups. While there were positive steps taken by APW to insure client adherence personal factors and internal issues within the organization and healthcare facilities are challenges towards client 100% medical adherence.

CONCLUSION AND RECOMMENDATION

This study is centered on understanding the barriers and facilitators of 100% medical adherence in HIV+ APW clients. The demographics of HIV+ clients of APW parallel most national demographic statistics which changed throughout time. This demographic transformation shows the shift from the popularly known 1980's demographic of wealthy white males to the now increasingly women and men of color with a background of low socio-economic status. Our research is timely because APW is looking to better understand the barriers that prevent its clients from adhering to their medical regimens. Once the organization obtains a more complete understanding of issues facing clients' adherence activities from our research, APW can use this information to further develop a holistic case management and service experience.

Throughout qualitative research, issues surrounding 100% *medical adherence*—completely and correctly following medication regimens as well as regularly attending case manager meetings and doctor appointments—became easily recognizable. Two major findings that influence medical adherence are self-efficacy as well as the logistics and mechanics of the healthcare system. *Self-efficacy*, a factor that is significant in understanding adherence, is the ability to make informed decisions, complete necessary tasks, and reach attainable goals. *Logistics and mechanics* of the healthcare system include social and economic barriers as well as structural issues that may prevent or support clients' adherence. These factors were identified through qualitative research completed at APW. Our recommendations are presented in the table below.

| Recommendations | | |
|--|--|--|
| | Case Managers | APW Administration |
| 1. Strengthen Chart Data Collection | <ul style="list-style-type: none"> • Create universal dialogue framework for case manager meets to allow more in depth conversations surrounding self-efficacy and logistics and mechanics of the healthcare system | <ul style="list-style-type: none"> • Create a universal charting system to establish universality among data collection • Bi-annual compilations of chart data collected |
| 2. Greater Support of Mental Health Needs | <ul style="list-style-type: none"> • Case managers strategically identify clients with mental health needs • Bolster increased attendance at support group meetings | <ul style="list-style-type: none"> • Increase the staffing and support for the APW Mental Health Department • Diversify services and referrals for mental health cases |
| 3. Increase Health Literacy | <ul style="list-style-type: none"> • Conduct workshops to educate clients on self-advocating in medical settings | <ul style="list-style-type: none"> • Create a network of service providers who are comprehensively supportive of APW clients |

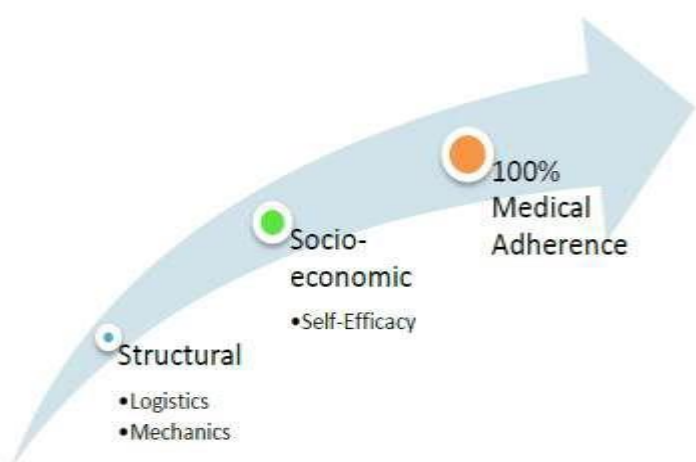
APW Adherence Advisors

Introduction

This study is centered around understanding the barriers to as well as facilitators of 100% medical adherence in HIV+ APW clients. The demographics of HIV+ clients of APW parallel most national demographic statistics which changed throughout time. This demographic transformation shows the shift from the popularly known 1980's demographic of wealthy white males to the now increasingly women and men of color with a background of low socio-economic status. Our research is timely because APW is looking to better understand the barriers that prevent its clients from adhering to their medical regimens.

Throughout qualitative research, issues surrounding 100% *medical adherence*—completely and correctly following medication regimens as well as regularly attending case manager meetings and doctor appointments—became easily recognizable. Two major themes in our research that influence medical adherence are self-efficacy as well as the logistics and mechanics of the healthcare system. *Self-efficacy*, a factor that is significant in understanding adherence, is the ability to make informed decisions, complete necessary tasks, and reach attainable goals. *Logistics and mechanics* of the healthcare system include social and economic barriers as well as structural issues that may prevent or support clients' adherence. These factors were identified through qualitative research completed at APW.

Findings



Our research suggests that in order for clients to maintain 100% medical adherence, they must have both high self-efficacy and adequate knowledge to navigate the logistics and mechanics of the healthcare system. In the population of clients that APW works with, clients have a low understanding and limited access to the logistics and mechanics of the health care system. In our research, factors that resulted in low self-efficacy include stress, social factors resulting from an individual's social environment, mental health barriers, drug addiction, disclosure, and discrimination based on HIV+ status. Our research also highlighted factors that formed barriers to a clients understanding and access of the health care system. These included issues with transportation, APW support, health insurance, healthcare provider, and medication issues. Overall, both the self-efficacy factors as well as the logistics and mechanics of the healthcare system proved to be further exaggerated in situations of poverty and limited resources.

Discussion

Recommendations

| | |
|---------------------------|--|
| 1. Universal Tool | <ul style="list-style-type: none"> • Create universal recording sheets for case manager meetings |
| 2. Mental Health | <ul style="list-style-type: none"> • Bolster increased attendance at support group meetings and target social issues with clients |
| 3. Health Literacy | <ul style="list-style-type: none"> • Conduct workshops to educate clients on self-advocating in medical settings |

ANNEX 2: ALL INTERVIEW QUESTIONS AND FOCUS GROUP QUESTIONS

Part 1. Informal Interview Structure for APW Case Managers

- What is medical compliance?
- Why is medical compliance important?
- What factors do you find most important/significant to client adherence or non-adherence?
- Does a case manager influence client adherence? If so how?
- Do you see yourself as an influence to your clients' adherence?

Part 2. Formal Interview Questions for APW Clients

Warm up questions:

- Tell me a little about yourself
- When were you diagnosed with HIV/AIDS?
- How did you learn about APW?
- When did you start coming here and why?

1. Describe your experience with AIDS Project Worcester.

- What resources do you use at APW?
- Can you describe your experience since you've come to APW?
- What do you like about it?
- What don't you like about it?

2. Describe your experience with your case manager.

- Do you have a case manager? If so, what is their job/role?
- Has it been important to you to have a case manager?
- Describe some of the services that they have done for you that have been helpful.
- What is your relationship like with your case manager? Do you like your case manager?
- In what ways do you rely on your case manager? What kinds of things do you get help

with from your case manager?

-Are there other things that you would like your case manager to help you with?

3. Experiences with the doctor.

- Do you have a doctor?

- If so, do you like your doctor?

- Are they helpful?

- How often are you supposed to see your doctor?

-How often do you go to your doctor?

-Think about the last time you went to see you doctor. Was it a positive experience? What did they advise you?

-Have you ever missed an appointment?

-Think back to the last time you did. Tell me a little about why you missed it. What happened?

4. Experiences with taking medication.

- Are you currently taking any medication right now for HIV/AIDS?

YES (currently on meds):

- What are they?

- When did you start taking this/these medication(s)?

- Did you take other HIV/AIDS medications before this one?

- Since being diagnosed, how many times have your medications changed?

- Why did you change medications? What role did side effects play?

-Think back to the last time you took the medication. How did you feel when you took it? Did you experience any side effects?

- Do you have a set routine for taking your medication? (Provide example)

- If so, what is it?
- How many times per day? When during the day? How do you remember?
- Do you need to have food with your medications?
- Is the routine you follow the same as your doctor explained for these medications?
 - Was the routine clear the way your doctor described it? Did you ask him/her questions? Was it confusing to start taking this/these medication(s)?
- What happens when you run out of medication?
 - Where do you get your refills? How do you get there?
 - How are you paying for your HIV/AIDS medication?
 - What are the challenges in getting refills on your medications?
- Do you have health insurance?
 - How did you learn about this insurance? Did anyone help you fill out the paperwork? Was it difficult to get this insurance?
 - Does the insurance cover all of your HIV/AIDS medication?
 - Have you had any problems with this insurance?
- Have you ever missed a dose of your medication?
 - Think back to the last time this happened. Why did you miss the dose?
 - How often does this happen?
 - When you skip a pill, what happens? How do you feel?
- Are you comfortable taking your medications when other people are around?
 - Do other people know that you are taking these medications?

NO (currently off meds):

- Can you tell me why you are not taking any medication?
- Have you ever taken medications for HIV/AIDS?

- If so, when did you start taking the medication?
- How many changes in medication did you go through?
- When did you stop taking them?
- What happened that made you stop taking them?
- What didn't you like about the medication?
- Do you have health insurance?
- How did you learn about this insurance? Did anyone help you fill out the paperwork? Was it difficult to get this insurance?
- Did the insurance cover all of your HIV/AIDS medication?
- Have you had any problems with this insurance?

6. Support system.

- When you were first diagnosed, how did you feel about it? Have your feelings changed over time?
- Have you told anybody about your HIV/AIDS status?
- Do you have people that you talk to about being HIV+?
- How has your life changed because of living with HIV?
- What are some of the things that have helped you deal with these changes?

7. What has been the hardest thing about living with HIV/AIDS?

8. What else is hard about living with HIV/AIDS?

9. Is there anything that would make your experience living with HIV/AIDS easier?

10. With this research project, my group members and I are trying to help APW figure out a better way to help clients take their medication. Is there anything else you can tell me about taking medication that would be helpful?

Part 3. Structure for Focus Group/Workshop

Structure of the workshop will be less like a focus group discussion and more **INTERACTIVE**. We will use a participatory technique that involves a sticker-rating chart.

1. Structure

- a. Roles: Facilitator (one of us) will explain the procedure and purpose of this workshop (there will also be a note taker and observer)
- b. Participants will be divided into groups of 3 or 4. The case manager will also participate in this activity.

2. Activity

- a. Each group will be given a large sheet of poster paper, markers, and 10 stickers per person.
- b. Each participant will have to write down as many barriers to adherence that they face or know that other people face.
- c. Within each group, each participant will then place stickers next to the issue they believe or feel is the greatest challenge for them. Participants have 10 stickers each and are allowed to place multiple stickers on one problem.

3. Discussion/Explanation –

- a. Once participants have finished, each group will explain their sticker chart to everyone else.

4. Light refreshments will be provided by researchers.

5. Should have at least one Case Manager present if possible.

ANNEX 3: CONSENT FORMS (INTERVIEW AND FOCUS GROUP)

INFORMED CONSENT FOR STUDY PARTICIPANT (INTERVIEW)

Title of Research Study: Factors influencing medical adherence of clients in Aids Project Worcester (APW)

People in Charge of Study:

| Name | Phone | Email |
|-----------------------|-----------------------|-----------------|
| Shan Yi Koay | skoay@clarku.edu | (985) 228-3956 |
| Anna Shayo | ashayo@clarku.edu | (774) 329-1591 |
| Amanda Major | amajor@clarku.edu | (413) 530-0882 |
| Jacqueline Osei-owusu | joseiowusu@clarku.edu | (508) 762-6367 |
| Abby Donahue | adonahue@clarku.edu | (617) 388-1320 |
| Maya Baum | mbaum@clarku.edu | (301) 518 9003 |

Researcher Supervisor: Ellen E. Foley, Ph.D
Clark University
950 Main Street
Worcester, MA 01610
Phone: +1 (508) 793 8817
Email: efoley@clarku.edu

About this Research Project:

The researchers, Shan Yi Koay, Anna Shayo, Maya Baum, Amanda Major, Abby Donahue, and Jacqueline Osei-Owusu working under the supervision of Professor Ellen Foley at Clark University, are researching the factors that either impede or support complete medical adherence for clients of AIDS Project Worcester. Your opinions and experiences as HIV positive clients at APW can help us better understand the challenges you face and the services available to you. In addition, it can help us understand factors that may impede or support full medical adherence.

You do not have to participate in this study. You can decide not to be interviewed.

You will not be getting paid for participation.

If you agree to participate, you will meet with the researchers once or twice for about 1 hour at APW to discuss your experiences as individuals diagnosed with HIV, your medical regimens and your experience at APW.

With your permission, the discussion will be recorded. The recordings will be stored securely on the researchers' computers, and will only be shared with the research supervisors. These recordings will be later destroyed three years after the end of the study. The consent forms will be stored in the International Development, Community, and Environment (IDCE) Department in a locked cabinet dedicated for this purpose.

There are no known direct risks or benefits to you or your family members for participating in this study. You may refuse to answer any question, stop the discussion, or ask to reschedule the meeting. These options are always available to you.

The possible benefits of participating in this study include promoting research and include providing APW and the community with insight into the experiences that clients have with taking HIV/AIDS medication (factors that impede or support medical adherence). The report will hopefully impact procedures for APW and increase medical adherence in HIV/AIDS clients.

The results of this research may be published or shared with the agency, but your name or identity will never be used in any publication or in any conversations with other people. All identifying information (including name, date or place of birth) will be removed from any data.

None of the services you receive here will be impacted by what you tell us since your identity will remain confidential. Before the interview, the researchers will assign a random code number to be used in relation to your answers to protect your identity. That way, what you say and who you are will not be linked.

Please contact any of the people above if you have questions about this project, or if you would like to obtain the final report based on this research.

INFORMED CONSENT FOR STUDY PARTICIPANT (INTERVIEW)

Statement of person agreeing to take part in this research study

STUDY TITLE: Factors influencing medical adherence of clients in Aids Project Worcester (APW)

RESEARCHERS: Shan Yi Koay, Anna Shayo, Maya Baum, Amanda Major, Abby Donahue, and Jacqueline Osei-Owusu

The process, aims, affiliation, risks and benefits of this study were explained clearly to me, and I freely give my consent to participate. I understand that I might be interviewed once or twice for approximately 45 mins – 1 hour each time, that there are no potential risks to me or my family members, and that my information and what I share will remain confidential, and cannot be traced back to me.

I was given a copy of this consent form for my records. I understand that if I have any questions, I can call or email any of the researchers or I can contact their supervisor, Ellen Foley, by phone at +1 (508) 793 8817 or by email at efoley@clarku.edu in addition to contacting their university directly at: Chair of the Institutional Review Board (IRB), Dr. James Elliott, Clark University, 950 Main Street, Worcester, MA 01610-1477; phone: (508) 793-7152.

| | | |
|--|--------------------------------|-------------|
| <hr/> | <hr/> | <hr/> |
| Name | Signature or thumbprint | Date |
| | | |
| I agree to be audiotaped (circle one): | YES NO | <hr/> |
| | | Initial |
| | | <hr/> |
| <hr/> | | <hr/> |
| Signature of person obtaining consent | | Date |

INFORMED CONSENT FOR STUDY PARTICIPANT (INTERVIEW, ORAL CONSENT)

Statement of person agreeing to take part in this research study

STUDY TITLE: Factors influencing medical adherence of clients in Aids Project Worcester (APW)

RESEARCHERS: Shan Yi Koay, Anna Shayo, Maya Baum, Amanda Major, Abby Donahue, and Jacqueline Osei-Owusu

The process, aims, affiliation, risks and benefits of this study were explained clearly to me, and I freely give my consent to participate. I understand that I will be part of a group discussion about the factors that either impede or support complete medical adherence for clients of AIDS Project Worcester that will last for approximately 1 hour. There are no potential risks to me or my family members, and while the researchers will remove my identity from all data, there is a risk that some of the information might be shared outside of the group by other participants.

I was given a copy of this consent form for my records. I understand that if I have any questions, I can call or email any of the researchers or I can contact their supervisor, Ellen Foley by phone at +1 (508) 793 8817 or by email at efoley@clarku.edu in addition to contacting their university directly at: Chair of the Institutional Review Board (IRB), Dr. James Elliott, Clark University, 950 Main Street, Worcester, MA 01610-1477; phone: (508) 793-7152.

Statement: The study participant, (ID/name) _____ refused or is unable to sign the form for reasons of confidentiality, anonymity, literacy and/or linguistic reasons. I have instead read her/his the consent statement above, and she/he has given consent to participate in this study.

Signature of person obtaining oral consent

Date

The person has orally agreed to be audiotaped (circle one):
Initial

YES NO _____

Signature of person obtaining consent

Date

If you obtain oral consent, make sure to log the name, date, and location of the interview in a spreadsheet.

INFORMED CONSENT FOR STUDY PARTICIPANT (FOCUS GROUP)

Title of Research Study: Factors influencing medical adherence of clients in Aids Project Worcester (APW)

People in Charge of Study:

| Name | Phone | Email |
|-----------------------|-----------------------|----------------|
| Shan Yi Koay | skoay@clarku.edu | (985) 228-3956 |
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Researcher Supervisor:

Ellen E. Foley, Ph.D - Clark University - 950 Main Street - Worcester, MA 01610 - Phone: +1 (508) 793 8817 Email: efoley@clarku.edu

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You do not have to participate in this study or the focus group. You will not get paid for participating, however, you will receive a \$6 gift card. If you agree to participate, you will meet with the researchers once for about 45 mins - 1 hour at APW to discuss your experiences as individuals diagnosed with HIV, your medical regimens and your experience at APW.

With your permission, the discussion will be recorded. The recordings will be stored securely on the researchers' computers, and will only be shared with the research supervisors. These recordings will be later destroyed three years after the end of the study. The consent forms will be stored in the International Development, Community, and Environment (IDCE) Department in a locked cabinet dedicated for this purpose.

There are no known direct risks or benefits to you or your family members for participating in this study. Focus group members will be asked to keep the information provided in the groups confidential; however, a potential risk that might exist for some would be that information in the focus group might be discussed outside the group by other participants and be traced back to you. If this is a potential issue for you, you are encouraged to ask for an individual interview with one of the researchers who would then be knowledgeable of and bound by confidentiality. You may refuse to answer any question, stop the discussion, or ask to reschedule the meeting. These options are always available to you.

The possible benefits of participating in this study include promoting research and include providing APW and the community with insight into the experiences that clients have with taking HIV/AIDS

medication (factors that impede or support medical adherence). The report will hopefully impact procedures for APW and increase medical adherence in HIV/AIDS clients.

The results of this research may be published or shared with the agency, but your name or identity will never be used in any publication or in any conversations with other people. All identifying information (including name, date or place of birth) will be removed from any data.

None of the services you receive here will be impacted by what you tell us since your identity will remain confidential. Before the interview, the researchers will assign a random code number to be used in relation to your answers to protect your identity. That way, what you say and who you are will not be linked.

Please contact any of the people above if you have questions about this project, or if you would like to obtain the final report based on this research.

INFORMED CONSENT FOR STUDY PARTICIPANT (FOCUS GROUP)

Statement of person agreeing to take part in this research study

STUDY TITLE: Factors influencing medical adherence of clients in Aids Project Worcester (APW)

RESEARCHERS: Shan Yi Koay, Anna Shayo, Maya Baum, Amanda Major, Abby Donahue, and Jacqueline Osei-Owusu

The process, aims, affiliation, risks and benefits of this study were explained clearly to me, and I freely give my consent to participate. I understand that I will be part of a group discussion about the factors that either impede or support complete medical adherence for clients of AIDS Project Worcester that will last for approximately 1 hour. There are no potential risks to me or my family members, and while the researchers will remove my identity from all data, there is a risk that some of the information might be shared outside of the group by other participants.

I was given a copy of this consent form for my records. I understand that if I have any questions, I can call or email any of the researchers or I can contact their supervisor, Ellen Foley, by phone at +1 (508) 793 8817 or by email at efoley@clarku.edu in addition to contacting their university directly at: Chair of the Institutional Review Board (IRB), Dr. James Elliott, Clark University, 950 Main Street, Worcester, MA 01610-1477; phone: (508) 793-7152.

| Name | Signature or thumbprint | Date |
|---|-------------------------|-------|
| I agree to be audiotaped (circle one): YES NO | _____ | _____ |
| | Initial | |
| Signature of person obtaining consent | | Date |

INFORMED CONSENT FOR STUDY PARTICIPANT (FOCUS GROUP)

Statement of person agreeing to take part in this research study

STUDY TITLE: Factors influencing medical adherence of clients in Aids Project Worcester (APW)

RESEARCHERS: Shan Yi Koay, Anna Shayo, Maya Baum, Amanda Major, Abby Donahue, and Jacqueline Osei-Owusu

The process, aims, affiliation, risks and benefits of this study were explained clearly to me, and I freely give my consent to participate. I understand that I will be part of a group discussion about the factors that either impede or support complete medical adherence for clients of AIDS Project Worcester that will last for approximately 1 hour. There are no potential risks to me or my family members, and while the researchers will remove my identity from all data, there is a risk that some of the information might be shared outside of the group by other participants.

I was given a copy of this consent form for my records. I understand that if I have any questions, I can call or email any of the researchers or I can contact their supervisor, Ellen Foley by phone at +1 (508) 793 8817 or by email at efoley@clarku.edu in addition to contacting their university directly at: Chair of the Institutional Review Board (IRB), Dr. James Elliott, Clark University, 950 Main Street, Worcester, MA 01610-1477; phone: (508) 793-7152.

Statement: The study participant, (ID/name) _____ refused or is unable to sign the form for reasons of confidentiality, anonymity, literacy and/or linguistic reasons. I have instead read her/his the consent statement above, and she/he has given consent to participate in this study.

Signature of person obtaining oral consent

Date

The person has orally agreed to be audiotaped (circle one):
Initial

YES NO _____

Signature of person obtaining consent

Date

If you obtain oral consent, make sure to log the name, date, and location of the interview in a spreadsheet.

ANNEX 4: CODE BOOK

CODE BOOK

Stress

Social and economic factors that cause clients to feel stressed and experience other negative emotions that may impede their ability or motivation to be adherent.

Transportation

Transportation is getting from where they lived to where they need services. A necessary component to adherence that clients constantly face difficulties with. This includes issues with transportation vouchers, distance to doctor or pharmacy, cost of transportation, lack of transportation, and so forth.

Social Factors

Involves factors that deal with relationships with family, friends. Factors emanating from one's social environment including family, friends, and other relations that either helps or impede adherence to medication. That includes cultural beliefs, religion, homelessness, stigma and so forth. Stigma could be a relationship with public. Homelessness could be in between social and economic...close but not quite a social factor.

Discrimination towards HIV infected person

Actions/inactions exhibited by others that express discrimination against HIV infected persons. This includes treatment from medical provider/staff, discrimination at health facilities and so forth. Due to these negative experiences, clients are less likely to visit and/or interact with their healthcare provider(s).

Health Care Provider Issues (Accessing the healthcare system)

Challenges encountered in accessing services from healthcare facilities, professionals and policies. This includes having too many appointments, dealing with doctors, pharmacies, nurses, care workers, insurance and so forth.

Medication Issues

Reasons for not adhering to medication; problems that APW clients face in taking medication and adhering to their medication regimens. These include side effects, having too many pills, oversleeping, having to refrigerate pills, and so forth.

Mental Health

Factors relating to the mental state of clients. These can be positive or negative. This includes, mental health diseases, positive attitudes, seeking mental health care, negative emotions, depression, denial, and so forth.

Drug Addiction

Clients who have difficulty being adherent due to their status as past and/or present substance abusers. This includes missing doses or doctors' appointments due to drug-affected state of

mind, taking drugs instead of medication, and so forth.

Disclosure

Clients' level of comfort in storing and taking their HIV medication around others (family, friends, public, strangers). This can affect their ability to take their medication due to shame, fear, and/or embarrassment. This includes not taking medication due to too many people around, keeping their HIV status private from family and friends, and so forth. However, it can also include clients whose family and friends are aware of their status and thus don't feel the need to hide their medication. Disclosure can inhibit and facilitate adherence. (Are those policies adherence issues or one step away from immediate adherence and could be directly contributing) done

APW Issues

Internal issues within the organization that make it harder for clients to be adherent. This includes client-case manager interaction/relationships, higher-level management, and so forth.

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