Stephen L Levin. Evaluating clinics' use and adaptation of technology to the unique barriers faced by at-risk, HIV-positive individuals in the development of medication adherence plans. A Master's Paper for the M.S. in I.S. degree. 04, 2016. 48 pages. Advisor: Mary Grace Flaherty

This research reports on a case study of Whitman-Walker Health, an urban clinic that serves at-risk patients who are HIV positive. Interviews were conducted with administrators and clinicians to gain insight into the medication adherence barriers faced by their patients, and also study the methods and technological adaptations the clinic employs to help overcome the barriers faced by their patients. The study found a well-developed workflow and adept use of technology to create and keep patients on a path of medication adherence.

## Headings:

Medication Adherence HIV/AIDS Text Messages SMS Social Media mHealth

# EVALUATING CLINICS' USE AND ADAPTATION OF TECHNOLOGY TO THE UNIQUE BARRIERS FACED BY AT-RISK, HIV-POSITIVE INDIVIDUALS IN THE DEVELOPMENT OF MEDICATION ADHERENCE PLANS.

By

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> > Approved by

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## **1. Introduction**

For almost fifty years, the world has been faced with the epidemic of HIV/AIDS. HIV/AIDS has spread throughout the US and the world, affecting every demographic of society. Although it peaked in 2005 with 2.4 million deaths in a single year (Advocacy, 2015), its lethality still hovers around 35 percent (Advocacy, 2015). In the US specifically, the epidemic has killed 306,885, with 5,302 dying in 2013 (Centers for Disease Control and Prevention, 2014).

We have made great strides in the treatment of HIV/AIDS partly due to the introduction of antiretroviral therapy (ART) (World Health Organization, 2015). Although highly effective when used correctly, HIV/AIDS medication requires a 95 percent adherence rate in order to maintain its utility (Reisner, et al., 2009). Missing just one dose can lead to virus mutation and potential drug resistance. (U.S. Department of Health & Human Services, 2009).

Despite this imperative for consistent use, the rate of medication adherence, or the act of taking drugs as prescribed, is extremely low in most populations. In a 2011 study, only about 50 percent of patients took their medications as prescribed (Brown & Bussell, April 2011). Non-adherence is particularly prevalent among at-risk demographics, which include those under age 25, those in a lower socioeconomic bracket, minority groups, or those identifying as part of the LGBTQ community (Assawasuwannakit, Braund, & Duffull, 2014; Kalichman, et al., 2014).

There is no single strategy that is "best" when addressing the issue of medication non-adherence within these susceptible populations (Peterson, Takiya, & Finley, 2003). Because of this, hospitals and clinics across the US have attempted to implement a variety of tactics and technologies in the hopes of reducing the cases of medication non-adherence in the HIV/AIDS populations they serve. Due to this diversity of HIV/AIDS treatment and medication adherence plans, there is a definite and urgent need to study the effectiveness of real-world implementations of technology-based medication adherence plans in hospitals and clinics.

This paper will review the current practices at the Whitman-Walker Health in Washington, DC. This clinic is located in a major metropolitan area and serves a disproportionately large segment of the at-risk demographics listed above. This research explores which technologies the clinic uses and how those technologies are used to forward the clinic's goal of full client medication adherence. The types and effectiveness of these medication adherence practices are also evaluated in the context of the current literature.

## 2. Research Question

What are the perceived barriers to medication adherence for HIV-positive, at-risk individuals, and what technological and methodological adaptations does Whitman-Walker Health implement to address these barriers and create comprehensive medication adherence plans for their patients?

## **3. Literature Review**

## **3.1 Medication Adherence**

In order to effectively integrate technology into a medication adherence plan, one must first understand the barriers to proper medication adherence. Several studies have examined the factors that may cause patients to be non-adherent with medication. One meta-analysis consists of 24 papers on HIV and 12 on hypertension. The authors found a direct relationship between age and adherence, noting that adherence decreases by eight percent for each decade a patient's age is decreased. They also found the number of times per day a patient was required to take their medication to be a contributing factor. Patients prescribed pills three times a day were 15–19 percent more likely to be non-adherent than those who had to take pills once a day (Assawasuwannakit, Braund, & Duffull, 2014).

Another meta-analysis of 127 papers considered medication non-adherence among patients with cardiovascular disease. The authors categorized the factors of nonadherence into three overarching groups: those that were patient specific, those that were physician specific and those that were institution specific (Brown & Bussell, April 2011).

Some of the factors that the authors categorized as patient specific were a patient's lack of understanding of their disease, a lack of patient agency in the creation of the treatment plan and a lack of medical information literacy in general. The authors also pointed to factors that affected patients of a lower socioeconomic class more than others, such as costs associated with health care, lack of transportation and lack of family support. The factors attributed to physicians included creating overly complex medication plans and a lack of communication with the patient about the adherence plan. When it comes to institutional factors, the authors pointed to high costs, poor use of technology, and minimal patient-physician communication (Brown & Bussell, April 2011).

Other studies focus on specific elements of non-adherence. One study examined the perception that alcohol has a negative interaction with medication, which is a more significant contributor to non-adherence than is the actual consumption of alcohol. Of the people who stopped or skipped their medication, a majority believed that their medication was adversely affected by drinking. (Although this belief was also held by a slight majority of people who did not skip their medication.) The study also found that people who stop taking their medication are more likely to continue to drink and skip their medication for consecutive days after (Kalichman, et al., 2012). Another study tested food insecurity and its relation to HIV medication non-adherence. The authors found that independent of all other poverty markers, food insecurity had a negative correlation with medication adherence (Kalichman, et al., 2014).

## 3.2 Technology's Influence on Adherence

Once we know some of the barriers to adherence, the next step is to understand the efficiency of technology in overcoming those barriers. One of the most common forms of technology used in medication adherence plans is text messaging for reminders and communication. Four studies reviewed here involved text message communications: three meta-analyses, and one study with insight into how to address privacy concerns (Kannisto, Koivunen, & Välimäki, 2014; Finitsis, Pellowski, & Johnson, 2014; Pellowski & Kalichman, 2013; Hailey & Arscott, 2013). The first meta-analysis considered 60 studies encompassing all medical conditions (Kannisto, Koivunen, & Välimäki, 2014). The only condition for inclusion in the meta-analysis was whether the study involved text messaging. The authors found a positive correlation between patients receiving text messages and medication or appointment adherence in 77 percent of the studies. Notably, patients' concerns about privacy were mentioned frequently.

The next two meta-analyses took small samples of papers specifically around HIV medication adherence (Finitsis, Pellowski, & Johnson, 2014; Pellowski & Kalichman, 2013). One meta-analysis specifically focused on text messaging and its effect on medication adherence, where the other took a more broad view of technology as it relates to medication adherence over a two-year period (Finitsis, Pellowski, & Johnson, 2014). The former found that when taken in aggregate, four factors of text messaging can cause a statistically significant increase in adherence. The first factor is the frequency of text messages. The authors found that messages sent between daily and weekly intervals were more effective than daily. The second factor is how the messages are sent. The authors found that bidirectional communication is best, speculating that this is either due to the ability of bidirectional communication to immediately troubleshoot problems, or that bidirectional communication helps to build trust with the provider. The third factor they identified is personalization of messages, as coded and personalized messages can help ensure patients' privacy. The fourth factor is sending out messages to match dosing schedule. Though, as the paper points out, this conflicts with the first factor, which does not recommend daily messaging.

The latter paper reviews technology-enhanced medication adherence practices between 2011 and 2012 (Pellowski & Kalichman, 2013). The study found that weekly cell phone calls were beneficial for both urban men and women in Atlanta, GA and a small sample group of adolescents. They also found a positive correlation between text messages and medication adherence among teens through 29-year-olds.

The last text messaging study reviewed here involves youth in the Baltimore metropolitan area, who were enrolled into a mix of text and social media communication streams with a mental health component called STAR TRACK (Hailey & Arscott, 2013). This study found a positive correlation between text reminders and adherence, but what set this paper apart was the innovative way the facilitators addressed privacy concerns when sending text messages out to clients. In this program, providers worked with clients to develop code that could be used to ask about adherence without giving out personal information—e.g., a text like "How are you?" could mean "Did you take your meds today?"

In an interview with the Manager of Medical Adherence, Nurse Care Manager Heather Alt at Whitman-Walker Health, it was found that many patrons without a phone or cell phones still have access to social media (Alt, 2014). The literature is still in its infancy when it comes to the use of social media and medication adherence in HIV/AIDS patients.

In one study of poor, African-American, homosexual men at a Philadelphia community clinic, due to clients' cell phones frequently being lost or stolen, the researchers found Facebook to be the most effective medium of communication (Daughtridge, Conyngham, Ramirez, & Koenig, 2014). There is scant additional research when it comes to social media as a replacement for cell phone and text messaging in the realm of medication adherence.

In the medical industry, mHealth is an overarching term that refers to any use of mobile phones to assist the medical profession. Currently, there is a lot of interest surrounding "mHealth," or mobile health. However, much of the current research is wary of full-scale endorsement of the use of "mHealth" (Anglada-Martinez, Riu-Viladoms, Martin-Conde, Rovira-Illamola, & Sotoca-Momblona, 2014; Tomlinson, Rotheram-Borus, Swartz, & Tsai, 2013; Hall, C. S., Fottrell, E., Wilkinson, S., & Byass, P., 2014). A 20-article meta-analysis found that the majority of mHealth studies were conducted in the developed world and although the majority of studies (65 percent) had positive outcomes, the sheer variety of study designs dissuaded the authors from giving a full endorsement of the technology (Anglada-Martinez, Riu-Viladoms, Martin-Conde, Rovira-Illamola, & Sotoca-Momblona, 2014). This sentiment was echoed both by a study that looked at the current field of mHealth and felt that no large-scale study has been conducted in the field (Tomlinson, Rotheram-Borus, Swartz, & Tsai, 2013) and a parallel meta-analysis of 76 mHealth papers that saw promise in the field of mHealth but questioned the limited number of large-scale studies on the effectiveness of mHealth (Hall, C. S., Fottrell, E., Wilkinson, S., & Byass, P., 2014).

As can be seen from the many barriers to medication adherence and the everevolving nature of technology, the need is clear to continue to expand research efforts into understanding the effects technology has and will have in medication adherence plans.

## 4. Methodology

This research was designed to be a case study conducted using interviews with clinic staff of Whitman-Walker Health. This was combined with background research about the clinic and the population it serves. The clinic has an above-average proportion of low-income, minority, LGBTQ-identified and/or homeless population who are HIV positive. Notably, this clinic offers free or highly discounted services to these communities and has an "open door" policy for members of the community who cannot afford to pay their medical bills.

Those who were interviewed for the study consisted of clinicians and staff who volunteered to be interviewed without compensation. The group interviewed included a lead administrator, three clinicians who serve as the first contact for patients just diagnosed with HIV/AIDS, and two late stage staff, whose jobs are to restart patients on their medication adherence path if they become non-adherent.

A series of in-person interviews was conducted in February, 2016 with the aforementioned clinicians and staff. Each interview lasted between 15-30 minutes and was conducted over the course of a work day. The questions were broken down into three areas: the current medication adherence plans used in daily practice, how technology is being used in their medication adherence plans, and general information about the population they serve. (See Appendix 1 for the list of questions asked.)

Initial questions about the medication adherence plans in use were intended to identify the overall structure of the plans and to establish a baseline for further

exploration. The questions focused on how the clinics get patients started on an adherence plan, the basic characteristics of the adherence plan, whether there are separate adherence plans for people at higher risk of non-adherence, what technologies the clinic uses as part of their adherence plans, if IT staff is available on site, and what questions the clinic staff may have about the technology they use. There were also more openended questions on the staff's feelings about technology, their self-reported level of technological aptitude, and their personal level of openness to implementation of new technologies.

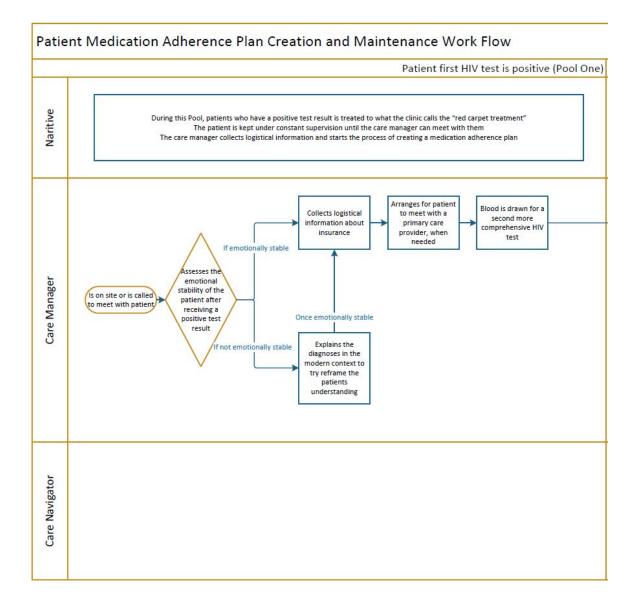
The questions about the clinic and the population they serve focused on general aggregate population characteristics such as patient age, income, gender identity, infection rates, and medication adherence levels, as well as the clinic's current staffing and funding level.

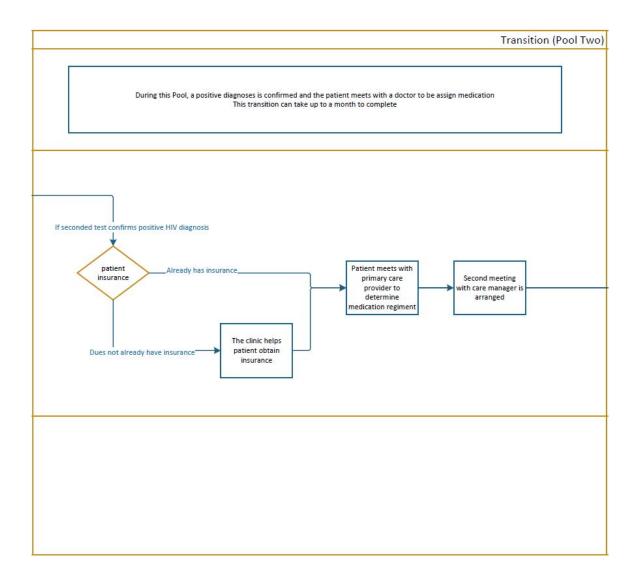
This study was approved by the UNC Chapel Hill Institutional Review Board.

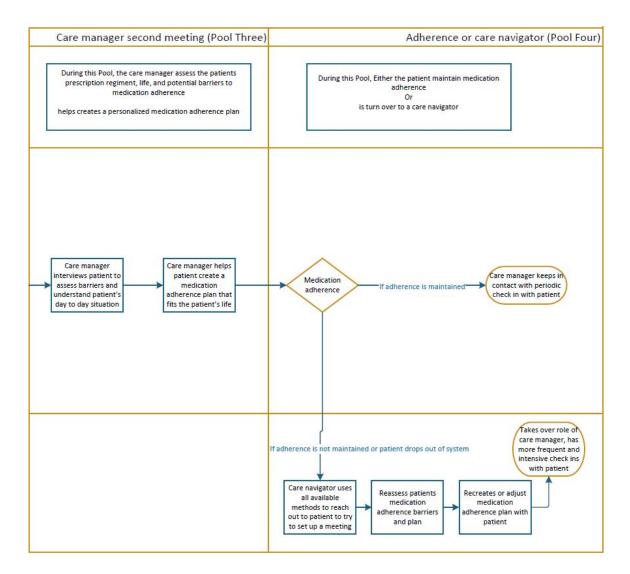
## 5. Results

## **5.1 Adherence Methods**

Whitman-Walker's approach to the assessment, creation and implementation of medication plans is akin to that of a series of cascading waterfalls. At the end of each waterfall, there is a "pool," or step in the process, that has a dedicated framework and set of objectives that need to be accomplished on the part of both the clinician and patient before the patient moves to the next step in the process. The process is unidirectional, in that once a certain "pool" has been passed through, it is not revisited by the same group of clinicians. Despite this seeming rigidity, the framework is flexible enough to adapt to the patient's level of commitment, understanding and emotional state. (See Figure 2.)







#### 5.1.1 Discovering a positive diagnosis

There are a variety of ways that patients first make contact with Whitman-Walker Health. Whitman-Walker both offers free HIV testing on site and also has a mobile van that travels around the city administering HIV tests. Other patients may have previously been diagnosed with AIDS or HIV, dropped out of the medication adherence program, and decided to come back, or have been relocated to Whitman-Walker from another facility or out-of-state.

#### **5.1.2** First contact

If a patient receives a positive result at any location, Whitman-Walker initiates what they call the "Red Carpet" approach. The first protocol in this approach does not allow the newly diagnosed patient to be alone without some health care representative attending to them. Both in the van and on site there is an on-call care manager who is called to meet with the patient immediately after the diagnosis is relayed to the patient.

## 5.2 The Role of the Care Manager

The care manager is essentially a project manager for the patients that are assigned to them. The care manager is in charge of ensuring the initial diagnosis was correct, that all logistics of the patient's care are taken care of (such as, if the patient needs to get insurance or obtain transportation compensation), but their main focus is assessing patients' ability to stick to a medication adherence plan, and helping create a medication adherence plan that the patient feels comfortable following. The care manager has a long term role of ensuring the patient sticks to their medication adherence plan, and adjusts the plan accordingly with changes in the patient's life.

#### 5.2.1 Care Manager First Meeting

This initial contact with the care manager is the first of a series of introductory meetings that the patient will have with the nurse care manager.

#### 5.2.1.1 Emotional Stability

The first variable the nurse care managers look for is the mental stability of the newly diagnosed patient. They try to assess if the patient is capable of talking about their new

diagnosis and if they are ready to talk about creating an action plan for themselves. If the patient is perceived not to be in the right mental or emotional space to create an action plan, the nurse care managers focus the first meeting on talking to the patient about HIV in the modern context. Some clients are not aware of the effectiveness of modern treatment compared to HIV treatments in of the 1980s and 1990s and will assume that a positive diagnosis for HIV means a significantly shortened life span. The care manager will talk about how things have advanced and with proactive steps, that one can insure longevity with a positive diagnosis.

There is no formalized set of questions used by the care manager to assess the emotional status of patients, but there is a common theme in all of the questions. Each care manager talks about the evolution of HIV treatment over the past decades, tries to dispel any myths that the patient may have about the disease, and gauges the patient's interest in the treatment and management of their disease. As of this writing, the clinic administration is currently in discussions to start incorporating an emotional and motivational evaluation system, currently being used by the clinic's patient care navigators, to help with this initial emotional assessment.

#### 5.2.1.2 Logistical Infrastructure

Once the assessment of the patient's emotional status is complete and the care manager feels confident that the patient is emotionally stable, the care manager moves to more focused questions regarding how the patient will get treatment. These questions include the patient's insurance status (and whether the clinic needs to provide resources for the patient to obtain insurance), and if the patient is able to see a primary care provider that day. Also during this time, the care manager will have blood drawn for a second, comprehensive blood test to screen for false positives from the patient's "First Contact" HIV test.

#### 5.2.2 Transition

After the first meeting, there is a three to four-week transition period, during which a patient gets their results back. If the second blood screening confirms a patient's HIV positive status, then the clinic helps arrange the needed paperwork related to insurance and the patient is assigned a primary care physician if they do not have one. During this transition period they meet with the primary care physician to assess their physiology and are assigned their medication for treatment. During this transitional period a second meeting is scheduled with the care manager.

#### 5.2.3 Care Manager Second Meeting

In this meeting the care manager considers the medication regimen the primary care physician has prescribed to the patient and works with the patient to practically assess how the patient will take the medication, identify some of the barriers the patient may face for proper medication adherence, and offer some practical solutions to address these barriers. As one interviewee described this meeting, "This meeting is to take the doctor's 'What' and to help the patient discover 'How'."

#### 5.2.3.1 Assessing Adherence Barriers

The care managers focus on some of the largest barriers to medication adherence, such as housing status, financial stability, access to food, support systems, and transportation. The staff also seemed to have clear understanding as to why they were asking questions about those elements of patient's' lives, and how they would tailor patients' medication adherence plans to the responses. (See Table 1.)

Table 1

Questions asked to patients	Rationale for asking the question
	If a patient does not have stable housing, the
	patient's medication could be stolen due to a
Housing status	lack of safe storage space
	If a patient does not have financial stability,
	they may skip medication, may have
	transportation issues, are more likely to have
Financial status and	a pre-paid phone (and that phone may get
stability	shut off)
	If a patient does not have access to food,
Access to food	they may skip medication
	If a patient does not have a support system,
	they may have to hide their medication from
	friends and family. If they are using a home
	phone, the clinic may need to use codes for
Support systems	communication.
	If a patient does not have reliable
	transportation, they need to set up
Transportation	alternative means or may miss appointments

	If a patient does not have a high
	technological aptitude, there has to be a lot
	more training on some of the medication
Technological aptitude	adherence technologies.

#### 5.2.3.2 Adherence Plan Creation

After analyzing the patient's responses to the questions regarding potential barriers, the care managers start working with the patients to create an adherence plan. This involves getting the patients familiar with the medication, detailing the medication adherence methods that might work best for them given their responses to the prior questions, and demonstrating how available technology could be integrated into the patient's adherence plan.

#### 5.2.3.3 Care Manager Question Diversity

There was diversity among the care managers as to the questions they asked when trying to assess the potential barriers to medication adherence and creating an adherence plan. Some of the care managers took a nuanced approach to their assessments by asking "day in the life" sorts of questions, such as "What time do you normally eat breakfast?" This question, according to one interviewee, can be used to assess both stability and work status while also giving insight into how to start integrating the medication into the patient's daily routine.

Other care managers took a more direct approach, asking things like "Have you ever missed taking medication in the past?" and "Is there someone in your life you trust talking about your status with?" Despite the diversity of approach, all the care managers seem like they are able to obtain the same information and make the same sort of assessments as to barriers facing their patients and the nature of the adherence plan that needs to be created.

## **5.3 The Role of the Patient Care Navigator**

For many patients, contact with the care managers is enough. Once the adherence plan is set up, the care managers follow up periodically in between the patient's scheduled visits with their primary care provider. However, patients who start missing their scheduled visits or have a tendency to miss multiple medication doses are assigned a Patient Care Navigator.

The patient care navigator's job is to locate the patients that have dropped out of the clinic's adherence program, convince them to come back into adherence compliance, identify why the patients fell out of compliance, and, if need be, create a new adherence plan based on the patient's individual situation.

#### **5.3.1** Connection to a Patient Care Navigator

Many of the patients assigned to a patient care navigator have previously dropped out of the system entirely. The first task of the care navigator is to make contact with these patients. The care navigators that were interviewed talked about the variety of communication methods they use, ranging from texts, phone calls, and emails, to sending paper mail to last known addresses of the patients.

#### 5.3.2 Patient Care Navigator First meeting

Once contact has been made with the patient, the patient care navigator tries to assess why the patient dropped out of the system and how to get the patient back on the medication adherence plan.

Both patient care navigators interviewed indicated that their first priority was to assess the motivation and engagement the patient had with their own care. They would often ask leading questions that they knew the answers to in order to assess how much the patient knew about their own treatment plan, their adherence level, and the medications they were taking. In addition to questions that they self generate, they use the Patient Activation Measure (PAM), a peer-reviewed survey used to measure a patient's knowledge of their disease and treatment, skills they currently possess, and confidence in using the knowledge and skills they have, to generate a numeric score for the patient's level of engagement. Patient care navigators administer PAM through Flourish, a health care interface created by Insignia Health, that combines the patient's PAM score with proprietary information to create an individualized assessment.

#### 5.3.3 Patient Care Navigator Patient Engagement

Although everyone involved in the system stays engaged with the patient, the patient care navigator makes frequent contact with the patient, which can include impromptu interactions such as texts and phone calls during non-standard work hours. The patient care navigator tries to place themselves apart from the system as a point of trusted support for the patient. Both care navigators interviewed indicated that patients often respond to their phone calls when the patient stops responding to calls from the clinic itself.

## **5.4 Technology Integration**

Whitman-Walker staff has integrated technology into every aspect of their medication adherence plans. There are two distinct categories that Whitman-Walker's technology falls into: technology as a way of communicating with patients, and technology as a way of enhancing medication adherence plans.

## 5.5 Technology as a way of communication

Whitman-Walker integrates a variety of technologies to communicate between their staff and their patients. All the interviewees had a similar hierarchy when it came to their preferred methods of communication with patients and the order in which they would use them to try to reach out to a patient when the patient failed to make an appointment.

#### 5.5.1 Two-way texting

Although not the preferred means of communication for staff and patients (half said it was their second method of choice), two-way texting was the most commonly reported method of communication. Five out of the six interviewees directly mentioned the use of two-way texting. They mentioned the versatility that texting gave them to send reminders, troubleshoot problems, and keep an open line of communication for the patient to interact with staff. It is used by both the care managers and the care navigators. One of the care navigators went into detail about the advantages of having the ability to communicate using a cell phone. If they feel they are not getting the whole story when they have a face to face with a patient, the care manager can text them afterwards and may gain greater insight into the barriers facing the patient through that mode of communication.

#### 5.5.2 Phone calls

Although the most preferred (three out of six), the second most common method of communication is via phone calls. One of the care managers reported this was the preferred method of some of their older patients. One of the care navigators found great value in phone calls from his work-issued "personal" cell phone, finding that patients who stopped responding to a phone call from the main hospital line would often answer phone calls from his particular cell phone.

#### 5.5.3 Email

Although none of the staff preferred email, all had used it as a means to try and communicate with their patients. Due to email's unencrypted nature, any communication sent through email has to be coded and can only have generic text without any identifiable HIPAA information. All an email will have, according to one care manager, is how long it has been from the patient's last appointment and a plea to contact the clinic. All the staff were aware of the limitations and privacy concerns of using email and so would try not to use it if possible.

#### 5.5.4 Postal Mail

While certainly not new or advanced technology, many of the staff found utility in using postal mail to reach out to patients who were the most difficult to reach. Both care managers and care navigators alike reported having success with postal mail when all other methods of communication failed. One care navigator related a story of a patient saying "I lost my cell phone but got your letter, so I'm calling you back to restart my

program."

## 5.6 Technology as a way of adherence support

#### 5.6.1 EMR One Way Text

Whitman-Walker has an established Electronic Medical Record (EMR) called eClinicalWorks. This EMR allows for different means of communication between clinicians and patients, including a one-way text messaging system from the EMR software itself. This feature is used primarily to send scheduled appointment reminders, and is used universally by all the staff. A consistent complaint among a majority of the interviewees was that the system is unreliable, sometimes not sending texts to the patient even when instructed, so it is not the preferred method of communication by the staff. Even so, one interviewee indicated that it is the preferred method of communication for younger patients who, among other reasons, liked the ability to show their employers a scheduled appointment reminder on their phone sent from the clinic. The majority of the staff felt comfortable, confident, and well-trained on the EMR software, so most of the blame for the unreliability of the system was placed on the software itself at least by one interviewee. Two other interviewees wanted to learn more about the EMR as they felt they weren't fully utilizing it to its full potential.

#### 5.6.2 Phone Apps

One of the care navigators noted that all the patients he sees have smartphones. Many of the other staff interviewed also talked about the use of phone applications in adherence plans. The phone application Medisafe, a basic pill reminder app, and Mango Health, a more robust health tracking app with pill reminder, was reported by several of the care managers as being a useful tool for helping patients keep track of their adherence by setting up reminders to take medication on time. Although no other apps were mentioned, including the app built into the EMR itself called Healow (eClinicalWorks, 2016), none of the staff seemed closed off to the option of integrating a new app into their system or building their own.

#### 5.6.3 Websites

An adherence-focused website mentioned by the Whitman-Walker staff was medicationplan.com (Figure 1). This site has many features that the staff who used it found useful, such as infographics to visualize patient data. Staff also mentioned the website mymedschedule.com, where clinic staff can enter patient medication data and print out a medication schedule for the patient to take home. The website was not universally loved by the staff; one care manager observed that the website "should be connected [to the EMR] but is not." This care manager went on to say they only had one client who loves the website but others don't, and that they "would love to see a program that could see real time adherence and monitoring." One staff member indicated that EMR integration may soon be a possibility but was not confirmed at the time of the interviews.

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edActionPlan allows providers to ocument and print patient-friend				an is an excellent patient education n resource for teaching patients	At-home medication errors common for young children

Figure 1- screen capture of MedActinPlan.com main page

## **5.6.4** Phone Reminders

All the staff indicated that phone reminders were an integral part of medication adherence plans. Phone reminders can manifest in two different ways. The first method uses the clock feature on the phone; as most medications need to be taken at the exact same time of day, having a recurring alarm can help act as a reminder for patients. The second method is through the calendar feature on a phone, which has more flexibility as to when and how often reminders are sent, and also allows for greater detail in the message. All of the health care providers interviewed indicated that they used phone reminders as a prominent tool in their medication adherence plans. This is especially true, according to one care manager, for her patients who use prepaid phones that run out of text and data capacity frequently. It is also commonly understood among the staff that it is necessary to help the patient set up the phone reminders immediately upon deciding that reminders are the proper adherence plan. For patients who do not know how to set up reminders themselves, the staff can set them up on the patient's behalf. Many of the interviewees felt that this was one of the most effective tools used in medication adherence plans.

### 5.7 Technology Not Currently Integrated

#### 5.7.1 Social Media

Although Whitman-Walker has an extensive social media presence with a "channel" on almost every major social network, they have been hesitant to integrate social media into medication adherence plans. The administrator interviewed indicated an increased risk for violating patient privacy, offering a potential scenario where a patient leaves their social media unattended and private information gets exposed to an unwanted individual. There was also concern for potential HIPAA violations. There was no interest among the staff to explore social media integration into the adherence program.

#### 5.7.2 Video conferencing

Although not currently integrated, video conferencing was of high interest to care managers, care navigators, and the administration. Most saw it as a means of adherence support, allowing the staff to conduct direct observational therapy remotely. They felt that this could save time and money on transportation for the patient and cut costs both in personnel and facility expenditures for the clinic. The largest barrier against integrating web video conferencing is a perceived lack of encryption and thus a potential HIPAA violation.

## 5.8 Staff Technology Training and Attitudes

Of those interviewed, all but one staff members (five out of six) felt they received an adequate level of training on the technology that they used at the clinic and in the patients' medication adherence plans. All of the staff were able to correctly identify the size of their IT support team and its role within the system. All but one of the staff members also felt comfortable with the technology that they used both for patient communication and for adherence support. The one dissenter did not feel like she was adequately trained in using the electronic medical record as a means of communicating with patients.

#### **5.9 Siloing of Technology Awareness**

An observed obstacle in Whitman-Walker's medication adherence program was that technological knowledge was not universally shared among staff. All the staff with the same title, such as "care manager," more or less all have the same awareness about the technologies available to them. Likewise, the care navigators seem to know and use all the same tools as all the other care navigators. However, the care managers and care navigators did not seem to share knowledge of technology across job roles. For instance, both of the patient care navigators had familiarity with and had fully integrated the Patient Activation Measure (PAM) into their medication adherence plans. However, despite the fact that many of the care managers mentioned that patient motivation is a factor they look at, none seem to be aware of PAM as a technological option.

This lack of sharing was true in the reverse as well. One of the patient care navigators, when they were asked what technology they would like to see integrated into their future medication adherence programs, wanted a medication tracking app that they could suggest to their patients. Apps with exactly this functionality, such as Mango Health and websites such as medicationplan.com, are currently known and are being used by most of the care managers.

The administration is aware of these inconsistencies and is taking steps to address it. For instance, as regards the Patient Activation Measure, there are preparations being made to introduce the technology to care managers. However, the administration did not did not discuss any other plan to integrate technologies across the department.

## 6. Discussion

Barriers to proper medication adherence for at-risk, HIV-positive individuals can be numerous and devastating. Such individuals can suffer from lack of transportation, lack of a robust support structures, homelessness, financial instability or lack of self motivation for treatment, among others. Each one of these barriers can influence how the clinic constructs its medication adherence plan for the patient and what technologies it will integrate into that plan.

Some methodological adaptations are structural and are part of the clinic's basic response protocol. An early example of this is not leaving a patient alone when they're first diagnosed with HIV/AIDS until they can be assessed by care manager. This helps patients who have emotional barriers have an instantaneous support structure. Having the first care manager meeting address insurance helps ensure that those who are not financially stable can have access to care. Both the care managers and care navigators act as impromptu support for patients until the patient can develop a support structure on their own, which the staff also helps the patient to create.

Technology also plays an important role in addressing medication adherence barriers. Not only do two-way texts and phone calls help with troubleshooting problems before they become adherence problems for the patients, they further help to build a support structure for the patients. Phone reminders and one-way texts help with the erratic or inconsistent schedules that some patients, particularly younger patients, may have.

With limited resources and a large community, Whitman-Walker has done an excellent job of creating a system that identifies medication adherence problems early and effectively while also implementing methodological and technological solutions and support for their patients to address their individualized needs.

## 7. Future Research

#### 7.1 Study of Adherence Plan Standardization

All but one of the interviewees felt that they created an individualized medication adherence plan for each patient. Although there are many factors, discussed previously, that impact the structure of a patient's adherence plan, these factors seem to just point to a predefined set of technologies or methods used by the clinic, rather than truly creating an individualized plan for each patient. For instance, an adherence plan that would be created for a homeless youth with very little support structure will perhaps look very similar to that of another similarly situated patient, regardless of other factors. This suggests it may be possible to construct a standardized medication adherence plan methodology that Whitman-Walker and other clinics could implement. However, a more comprehensive, exhaustive exploration of individualized medication adherence plans would need to be undertaken to validate this hypothesis.

## 7.2 "Personal" Work Cell Phone

As indicated earlier the "personal" work cell phone is a valuable tool for one of the care navigators, both to connect with patients that were not giving the "full story" in a face to face setting and as a last resort way of reaching out to patients who were avoiding official clinic communications. For these reasons, the "personal" work cell phone seems like a promising tool worth exploring. Future study is needed as to why this cell phone is such an effective tool for the care navigators and if this method of personalized communication that is connected to but seemingly independent of the organization can be replicated in other settings.

# 7.3 Care Manager Question training

As covered earlier, there was diversity among care managers as to what questions they asked their clients and how they evaluated their clients, such as using the indirect method of covering the day in the life of the patient and the more direct method of asking targeted questions. A comparative study focused around the type of questions asked by the care managers, the evaluation methods used, and patient outcomes could help indicate a preferred method of information gathering.

# 7.4 EMR Training

The staff's interaction with the EMR system is worth further study as well. Many cited the problem of texts not being sent by the system when instructed. A few commented that they did not feel like they were fulling utilizing the system. This was confirmed in this research, as there is an app available from eClinicalWorks that the staff did not know about. It would be worth exploring the staff's knowledge of the EMR, if additional training would help the staff better use the EMR and what effect that would have on medication adherence plans.

# 8. Limitations

There are some limitations of this study that must be considered when assessing its generalizability. Due to time constraints for the busy staff, the amount and detail of the interview questions were limited and not open-ended to ensure no interview exceed the finite interview time allotment.

For this case study only six interviews were conducted: two care navigators, three care managers, and one administrator who also takes on the functions of a care manager. This is by no means a comprehensive survey of the entire staff, and therefore some information about the clinic's methodologies and technologies may have been missed. Those interviewed were also self-selecting volunteers, who may have a different view about their work than those who did not choose to volunteer their time for the study. Like all case studies, the restrictions of a single-site, in-depth case study limits the ability of the researcher to make a comparative analysis and for the results to be generalized.

Additionally, there are several factors about the community Whitman-Walker serves that may make it unique among like organizations. Some of Whitman-Walker's patients may face a lower transportation barrier on average compared to patients of other clinics. One of the interviewees discussed how some insurance companies in Washington, DC provide public transportation subsidies for their customers for medical purposes. Coupled with this is the fact that the public transportation system in DC is one of the most developed in the United States (University of Minnesota, 2014; FischerBaum, 2014; Stone, 2014). As transportation is one of the largest barriers to medication adherence, evaluating the efficacy of this program should take into account the higher than average access to transportation of Whitman-Walker patients.

Although Washington, DC has made significant steps to addressing its rate of HIV infection (District of Columbia Department of Health, 2012), it still has one of the highest rates of new HIV diagnoses in the county (onlinedoctor.superdrug.com, 2016). Because of this it receives a disproportionate amount of HIV grant funding comparatively for its size and population (Kaiser Family Foundation, 2016). More funding and resources may be available to this clinic and other DC clinics than may be available at other medical facilities, potentially allowing for specialization of staff and more advanced/expensive technologies to be integrated into medication adherence plans.

# 9. Conclusion

This research reviewed the methods and technology used by the staff of Whitman-Walker Health in Washington, DC in the creation and execution of medication adherence plans for patients who test positive for HIV or AIDS . This research explores which technologies this clinic uses and how those technologies are used to forward the clinic's goal of full client medication adherence. The types and effectiveness of these medication adherence practices are also evaluated in the context of the current literature.

The research found a well-developed workflow that had a dedicated care manager helping patients create an individualized medication adherence plan based on characteristics that affect a patient's ability to stay in adherence. For patients who have chronic adherence issues or who leave the system entirely, there are dedicated care navigators who try to reassess and reestablish a medication adherence plan.

The staff uses a variety of technologies both to communicate with patients and as a component of adherence plans. For communication the staff uses a mix of text, phone, email, and letters. As part of adherence plans, the staff sets up phone reminders, trains patients on phone apps, and sends automatic texts.

Overall Whitman-Walker Health has well developed methods to help patients create and stick to a fully developed medication adherence plan. They efficiently and strategically integrate technology to both enhance their operation and their patients' ability to adhere to their medication regimens. With a few modifications these methods could be generalized and copied for use in clinics around the US and the world.

# **Bibliography**

- Advocacy, U. C. (2015, 10 05). *FACT SHEET 2014*. Retrieved from UNAIDS: http://www.unaids.org/en/resources/campaigns/2014/2014gapreport/factsheet
- AIDS.GOV. (2015, 10 05). WHO IS AT RISK FOR HIV? Retrieved from AIDS.org: https://www.aids.gov/hiv-aids-basics/prevention/reduce-your-risk/who-is-at-risk-for-hiv/
- Alt, H. (2014, 11 19). Manager of Medical Adherence Nurse Care Managers. (S. Levin, Interviewer)
- Anglada-Martinez, H., Riu-Viladoms, G., Martin-Conde, M., Rovira-Illamola, M., &
  Sotoca-Momblona, J. (2014). Does mHealth increase adherence to medication?
  Results of a systematic review. *The International Journal of Clinical Practice*, 9-32.
- Assawasuwannakit, P., Braund, R., & Duffull, S. (2014). A model-based meta-analysis of the influence of factors that impact adherence to medications. *Journal of Clinical Pharmacy and Therapeutics*, 1-8.
- Brown, M., & Bussell, J. (April 2011). Medication Adherence: WHO Cares? *Mayo Clin Proc.*, 304 - 314.
- Centers for Disease Control and Prevention. (2014, 11 25). *HIV in the United States: At A Glance*. Retrieved from Centers for Disease Control and Prevention: http://www.cdc.gov/hiv/statistics/basics/ataglance.html

Daughtridge, G. W., Conyngham, S., Ramirez, N., & Koenig, H. C. (2014). I Am Men's Health: Generating Adherence to HIV Pre-exposure Prophylaxis (PrEP) in Young Men of. *Journal of the International Association of Providers of AIDS Care* (JIAPAC).

District of Columbia Department of Health. (2012). Annual Epidemiology & Surveillance Report. Department of Health. District of Columbia: District of Columbia Department of Health. Retrieved from http://doh.dc.gov/sites/default/files/dc/sites/doh/publication/attachments/2012AES RFINAL.pdf

- eClinicalWorks.com. (2016). Patient Engagement. Retrieved from https://www.eclinicalworks.com/products-services/patient-engagement/
- Finitsis, D. J., Pellowski, J., & Johnson, B. (2014). Text Message Intervention Designs to Promote Adherence to Antiretroviral Therapy (ART): A Meta-Analysis of Randomized Controlled Trials. *PLOS ONE*, 1-10.
- Fischer-Baum, R. (2014, Jul 31). *How Your City's Public Transit Stacks Up*. Retrieved from Five Thirty Eight: http://fivethirtyeight.com/datalab/how-your-citys-publictransit-stacks-up/
- Hailey, J., & Arscott, J. (2013). Using Technology to Effectively Engage Adolescents and Young Adults into Care: STAR TRACK Adherence Program. JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE, 582-587.
- Hall, C. S., Fottrell, E., Wilkinson, S., & Byass, P. (2014). Assessing the impact of mHealth interventions in low- and middle-income countries – what has been shown to work? *Global Health Action*, 7(0)

- Kaiser Family Foundation. (2016). *Total Federal HIV/AIDS Grant Funding by Agency*. Retrieved from kff.org: http://kff.org/hivaids/state-indicator/total-federal-grant-funding/#table
- Kalichman, S., Grebler, T., Amaral, C., McNerey, M., White, D., Kalichman, M., . . .
  Eaton, L. (2012). Intentional Non-Adherence to Medications among HIV Positive
  Alcohol Drinkers: Prospective Study of Interactive Toxicity Beliefs. *J Gen Intern Med*, 339-405.
- Kalichman, S., Hernandez, D., Cherry, C., Kalichman, M., Washington, C., & Grebler, T.(2014). Food Insecurity and Other Poverty Indicators among People Living with HIV/AIDS: Effects on treatment and Health Outcomes. *Springer*, 1133-1139.
- Kannisto, K. A., Koivunen, M. H., & Välimäki, M. A. (2014). Use of Mobile Phone Text
   Message Reminders in Health Care Services: A Narrative Literature Review. J
   Med Internet Res, 16. Retrieved from http://www.jmir.org/2014/10/e222
- onlinedoctor.superdrug.com. (2016). Sexually Transmitted Diseases Across Space and Time. Retrieved from onlinedoctor.superdrug.com/:

https://onlinedoctor.superdrug.com/std-us-eu/

- Pellowski, J., & Kalichman, S. (2013). Recent Advances (2011-2012) in Technology-Delivered Interventions for People Living with HIV. *Curr HIV/AIDS*, 1-13.
- Peterson, A., Takiya, L., & Finley, R. (2003). Meta-analysis of trials of interventions to improve medication adherence. *American Society of Health-System Pharmacists*, 657 - 665.

- Reisner, S. L., Mimiaga, M. J., Skeer, M., Perkovich, B., Johnson, C. V., & Safren, S. A.
  (2009, Feb-Mar). A review of HIV antiretroviral adherence and intervention studies among HIV-infected youth. *Topics in Antiviral Medicine*, 17(1):14-25.
- Stone, M. (2014, Jan 30). The US Cities With The Best Public Transportation Systems. Retrieved from Business Insider: http://www.businessinsider.com/cities-withbest-public-transportation-systems-2014-1
- Tomlinson, M., Rotheram-Borus, M., Swartz, L., & Tsai, A. (2013). Scaling Up mHealth: Where Is the Evidence? *PLOS Medicine*, 1 - 5.
- U.S. Department of Health & Human Services. (2009, 08 07). *Medication Adherence*. Retrieved from AIDS.org: http://www.aids.gov/hiv-aids-basics/just-diagnosedwith-hiv-aids/treatment-options/medication-adherence/
- University of Minnesota. (2014). *Access Across America: Transit 2014*. Retrieved from Accessibility Observatory:

http://ao.umn.edu/research/america/transit/2014/index.html

World Health Orginization. (2015, 10 05). *Number of deaths due to HIV/AIDS*. Retrieved from World Health Orginization:

http://www.who.int/gho/hiv/epidemic\_status/deaths\_text/en/

# **Appendix 1**

### SECTION 1: GENERAL CHARACTERISTICS OF MEDICATION ADHERENCE PLANS

GC-Q1) A patient who has just been diagnosed with HIV has been assigned to you, can you walk me through the process of creating a medication adherence plan for that individual?

#### GC-Q2) Would you say your group:

Has more or less the same plan for each patient that comes into the clinic?

Has predefined groups of medication adherence plans and decides what patients go in each group based on a set of predefined questions?

Or, do you completely create a specialized medication adherence plan for each patient?

## JF THEY ANSWER "A" TO QUESTION GC-Q2

GC-Q3a) Tell me about that plan.

### IF THEY ANSWER "B" TO QUESTION GC-Q2

GC-Q3b) How many groups do you have?

GC-Q4b) Can you tell me the general characteristics of each of those groups?

GC-Q5b) What are the questions you ask that help you decide what patient goes into what group?

GC-Q6b) What are you looking for when you ask those questions?

## IF THEY ANSWER "C" TO QUESTION GC- Q2

GC-Q3c) What are the questions you ask that help you create a plan?

GC-Q4c) What are you looking for when you ask those questions?

#### SECTION 2: TECHOLOGY QUESTIONS

T-Q1) Turning now to the technologies that are integrated into your patients' medication adherence plans. Can you describe the technologies that are available to your patients that can be integrated into their medication plans? Examples would be cell phones, smart phones, internet access, and computers.

T-Q2) Can you tell me how you use each one of the technologies you listed? For example, if you said cell phone. Would you use it to send a text message? Set a calendar reminder? And/or set an alarm clock reminder?

T-Q3) Do you know how much it costs to operate those technologies? For instance, if you use text messaging, do you know how much it costs to send a text from Whitman-Walker?

T-Q4) Do you have full-time IT staff to help with some of the technologies you use?

T-Q5) Is there a dedicated person who uses the technologies or is everyone responsible for the use of the technology?

T-Q6) If you use the technologies, how confident do you feel using them?

#### IF THEY ANSWER "A" TO QUESTION GC-Q2

T-Q7a) You said that you have more or less a standardized plan, do you use all of those technologies in that standard plan?

## IF THEY ANSWER "B" TO QUESTION GC-Q2

T-Q7b) You said your medication adherence plans are group based. Can you tell me what technologies are associated with each of the groups you described before?

T-Q8b) Can you tell me how the use of those technologies changes between groups?

IF THEY ANSWER "C" TO QUESTION GC- Q2

T-Q7c) You said you made an individualized medication adherence plan for each person. Can you tell me the most common forms of technology you use in the individualized medication adherence plans?

T-Q8c) Can you talk about any technology that you have used in an individualized medication plan that you rarely used or never used again? Please remember, I don't want personal information about the patients, just the circumstances as to why that technology was used and not brought into other medication adherence plans?

T-Q9) Are there any technologies that you currently don't use but would want to integrate into your medication adherence plans?

SECTION 3: ADMINISTRATIVE INFORMATION (to be asked just to the administrative staff)

What percentage of the clinic patients are:

- PI-Q1) Under age 25?
- PI-Q2) Make less than \$25,000 a year?
- PI-Q3) Identify as something other than heterosexual?
- PI-Q4) Are individuals that are HIV positive or has the AIDS virus?

PI-Q5) How many patients does an average clinician communicate with per week using technology (not face to face)?

PI-Q6) How much money does your clinic spend on technology that relates to your medication adherence plans?

PI-Q7) Are there any technologies that you currently don't use but would want to integrate into your medication adherence plans?

PI-Q8) What are the major barriers to integrating that technology?