Southern California CSU DNP Consortium

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IMPROVING HIV TREATMENT PROGRAM ADHERENCE IN AN ETHNICALLY DIVERSE URBAN CLINIC

A DOCTORAL PROJECT

Submitted in Partial Fulfillment of the Requirements

For the Degree of

DOCTOR OF NURSING PRACTICE

By

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ABSTRACT

Antiretroviral treatment in individuals infected with HIV is effective in increasing life expectancy beyond the known natural course of the disease. People who are HIV positive are likely to conceal their status, especially those from cultures that emphasize specific gender roles regarding sexuality. Fear of discovery and secrecy increases the risk of HIV transmission and interferes with patients seeking and adhering to treatment regimens. This descriptive study used semi-structured interviews with care providers to gather information regarding factors that contributed to non-adherence to HIV treatment regimens, and strategies they employed to increase the rate of HIV treatment adherence. Social cognitive theory and the logic model were the conceptual frameworks used to guide the project. Participants included 12 ethnically diverse care providers between the ages of 28 to 62 years from three HIV treatment clinics. Themes identified as contributing to poor treatment adherence were mental health status, homelessness, and stigma related to a positive HIV status. Healthcare system barriers related to the lack of cultural diversity among providers, bureaucratic issues relating to insurance coverage, and limited access to specialized services. This doctor of nursing practice project demonstrated the need for further investigation on how factors within the healthcare system affect HIV treatment adherence. Another need is to evaluate the effectiveness of assessment tools used to identify clients at high risk for treatment non-adherence.
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This project is dedicated to the memory of every loved one, whose health challenges, struggles, and will to live helped in understanding and advancing HIV/AIDS treatment. My work in this project is especially dedicated to my mother, Joyce Dobson and my grandmother, Gladys Brown, who inspired me to become a nurse.
BACKGROUND

Human Immunodeficiency Virus (HIV) is transmitted through body fluids and affects the immune system, specifically the CD4 cells (CDC, 2015). The virus progresses to destroy these T cells and limits the body's ability to resist infectious disease, resulting in Acquired Immune Deficiency Syndrome (AIDS). HIV is a lifetime disease without any known cure (CDC, 2015; Sharp & Hahn, 2011). The use of antiretroviral treatment (ART) in individuals infected with HIV has proven to be effective in increasing the life expectancy beyond the known natural course of the disease (CDC, 2015; Demmer, 2003; Remien et al., 2003; Sharp & Hahn, 2011).

The disease progresses through three stages: acute infection, clinical latency and acquired immunodeficiency syndrome (CDC, 2015). Acute retroviral syndrome or primary phase manifests as flu like symptoms, lasting two to four weeks, follows initial infection with the virus but in many instances may be asymptomatic (CDC, 2015). The clinical latency phase, also known as chronic stage, is often asymptomatic and may last for a number of decades especially in people receiving ART (CDC, 2015). The end stage of the disease involves the proliferation of the HIV virus in destroying the CD4 cells to levels below 200 cells per cubic millimeter of blood (CDC, 2015). At this point the immune system is weakened, increasing the susceptibility to opportunistic diseases. The progression to time of death varies in each individual and may be prolonged with proper treatment (CDC, 2015; Sharp & Hahn, 2011).

This project is focused on assessing treatment adherence behaviors of individuals in the clinical latency phase of HIV as perceived by their treatment care providers. Studies show that patients who are at least 95% adherent to their ART maintain their
CD4 count within acceptable normal limits (Castro et al., 2015; Demmer, 2003; Lester et al., 2010; Remien et al., 2003; Sharp & Hahn, 2011; Sullivan et al., 2008). HIV treatment guidelines from the Department of Health and Human Services (DHHS) specify that antiretroviral drugs must be taken correctly at least 95% of the time in order reduce the viral load (Lester et al., 2010; Scheid, 2007; Sharp & Hahn, 2011; Sullivan et al., 2008). Since the emergence of HIV/AIDS, several research studies of varying design and approaches have been conducted to probe the challenges associated with the nature and treatment of the disease (Chattu, 2015; Costa et al., 2012; Remien et al., 2003; Stricker et al., 2014). Research has helped to increase understanding of the disease process and advanced management modalities in order to improve adherence rates (Laws et al., 2012; Remien et al., 2003; Sharp & Hahn, 2011; Stricker et al., 2014).

There are several factors associated with why People Living with HIV/AIDS (PLWHA) do not adhere to their treatment regimens (Castro et al., 2015; Demmer, 2003; Lester et al., 2010; Penn, Watermeyer, & Evans, 2011; Remien et al., 2003; Sharp & Hahn, 2011; Young et al., 2014). Most studies have focused on the practices and perceptions of the HIV positive clients in reference to treatment adherence and not on that of the role of the healthcare provider in the clients’ adherence behaviors (Castro et al., 2015; Penn et al., 2011). There is a paucity of research relating to the health care system and the evaluation of the providers who participate in the treatment of PLWHA at it relates to their adherence (Castro et al., 2015; Laws et al., 2012).

**Problem Statement**

Since the discovery of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) in the early 1980’s, over one million people are
known to be infected worldwide (CDC, 2015; Sharp & Hahn, 2011; Vatanoglu & Ataman, 2011). Over 10,000 people die annually from HIV/AIDS in the United States (CDC, 2015; Valdiserri, 2011). The treatment of HIV/AIDS remains a challenge for health care providers and a burden for society on a global scale (Brawner, 2014; Saleh et al., 2011; Vatanoglu & Ataman; 2011). The toll to treat this disease is felt mainly among poor and disenfranchised people and plays a role in attitudes towards treatment adherence (Chattu, 2015; Costa et al., 2012; Kalichman & Grebler, 2010). Although the disease has no infective preference for a particular social strata, race or gender, several lifestyle factors contribute to its transmissibility among homosexuals, transgender males, and intravenous drug users (Chattu, 2015; Costa et al., 2012; Remien et al., 2003). Studies have shown that there is higher risk among people whose culture emphasizes specific gender roles regarding sexuality (Arnold, Rebchook, & Kegeles, 2014; Peter, Kamath, Andrews, & Hegde, 2014; Saleh et al., 2011). There is a traditional opposition against homosexuality among some African American cultures (Saleh et al., 2011). Homosexuality is believed to be inconsistent with their cultural values regarding manhood and masculinity (Saleh et al., 2011). This perception may lead to secrecy among some African American males who engage in sexual encounters with other men. They often do not see themselves as homosexual and may typically engage in unprotected sex with both males and females (Saleh et al., 2011). These individuals merely believe they are having sex. This practice and secrecy increases the risk of transmissibility of HIV among the population and limits their tendency to seek or adhere to treatment regimens (Saleh et al., 2011). It also prevents possible interventions by health care providers who are otherwise unaware of their needs (Saleh et al., 2011).
Although there remains room for de-stigmatization, over the past three decades, the perceptions and attitudes towards PLWHA has improved tremendously from in the mid 1980s, when little was known about the disease (Penn et al., 2011; Saleh et al., 2011). Much of this progress is contributed to the selfless interventions and attention drawn to the disease by those adversely affected either by being infected, or by association through their work and or community responsiveness (Sullivan et al., 2008). One such individual was Ryan White, a teenager with hemophilia, reportedly diagnosed with HIV following a blood transfusion. (Sullivan et al., 2008). The ridicule and segregation he met in his school and hometown led to a court battle and the relocation of his family (Sullivan et al., 2008). The situation drew the attention of several celebrities and government officials nationally and led to increase awareness of HIV/AIDS globally (Sullivan et al., 2008). Following his death in 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was enacted by congress to prioritize and allocate HIV/AIDS services (Sullivan et al., 2008).

The primary HIV treatment clinic in which the study was conducted is primarily a Ryan White funded clinic. The clinic maintains a database of the people enrolled in the treatment program and reported a history of low adherence among some clients. It provides support with medical and social needs through scheduled appointments and referrals as needed. Clients who are classified as a high health risk (HHR) due to poor adherence to their treatment regime are referred to the Medical Care Coordinators (MCC) for more focused management to identify and address their specific needs. The Medical Care Coordination program was established in the Division of HIV and Sexually Transmitted Disease [STD] Programs (DHSP) in the California Department of Public
Health (CDPH). The team consists of a registered nurse, a social worker and a medical case worker and have specific job functions and clear guidelines for their roles in the program. These coordinators completed a comprehensive assessment of the client’s health, and psychosocial needs in 12 domains: (1) Health Status; (2) Quality of life/Self care; (3) Antiretroviral Access and Adherence; (4) Medical Access, Linkage, and Retention; (5) Housing Situation; (6) Financial Stability; (7) Transportation; (8) Legal Needs/ End of Life Needs; (9) Support Systems and Relationships; (10) Risk Behavior; (11) Alcohol/ Drug Use and Addiction; and (12) Mental Health (Medical Care Assessment Guidance, accessed June 2015). The assessment is completed following client consent using the Casewatch electronic system and an individualized care plan developed to address the needs. This care plan is discussed with the client who has the opportunity to determine what they consider to be the priority needs. Once this is determined, the client and the MCC work together to ensure the goals of the plan are met. Follow-up procedures are established in order to increase adherence, increase interventions and supports and or facilitate discharge of self managed patients from the MCC. Clients are classified based on acuity from severe, high to self managed (Medical Care Assessment Guidance, June 2015). For example, a client is classified as HHR if they meet any of the following criteria: missed two consecutive follow up doctor's appointments, was diagnosed with a sexually transmitted infection (STI) within the past six months and or have a viral load above 400.

In December 2014, there were 78 clients on the MCC register at the primary project clinic, one third of who were reported to be non-adherent. In other words, they did not report for at least two to three follow up appointments and or did not return telephone
calls. The MCCs were able to identify several reasons for non-adherence, similar to factors commonly reported in the literature. These included issues such as interference with work and other schedules, lack of family and social support, lack of transportation, medication side effects, substance abuse, homelessness and mental health issues (Aragonés et al., 2011; Ramirez-Valles et al. 2013; Saleh et al., 2011).

**Purpose Statement**

The overall goal of this project was to understand the role and perspective of the healthcare providers in facilitating and improving treatment adherence of high-risk clients in an ethnically diverse urban HIV treatment clinic. One objective of the project was to identify the factors that contributed to non-adherence as perceived by the healthcare providers. A second objective was to develop recommendations for improving treatment adherence resulting from the information gathered from the healthcare providers. Health care providers at select treatment clinics were interviewed to help provide an understanding of the current treatment management processes. There were two primary project questions: What are the main factors that contribute to client’s non-adherence to HIV treatment regimen? and How may health care providers increase the rate of HIV treatment adherence among people living with HIV/AIDS? The information obtained from the interviews were used to identify gaps in the methods being implemented at the clinics to help clients adhere to their treatment programs.

**Supporting Framework**

The case management process is an evaluation grounded in understanding the social cognitive dynamic that is involved with human behavior in relation to their environment and available resources. Conceptual frameworks or theories provide a
foundation on which to build knowledge, develop interventions, and evaluate outcomes (Michielsen et al., 2012; Prestwich et al., 2014). Coates et al states that much of the observable success in HIV prevention is attributed to behavior change (Coates et al., 2008). There are several theories in health promotion research that are geared toward providing an understanding of health related behaviors and identifying targets for interventions. The Logic model and Social Cognitive Theory (SCT) are identified as appropriate conceptual frameworks for program evaluations (Michielsen et al., 2012).

Social Cognitive Theory (SCT), one of the most prominent theories used to interpret the interactions and actions of the individuals, describes a cognitive behaviorally based method of learning (Dewar et al., 2013; Glanz & Rimer, 2005; Michielsen et al., 2012). The theory was developed by Albert Bandura who expanded on the social learning theory through adding a construct to address self efficacy (Bandura, 1997; Bandura, Adams, & Beyer, 1977; Glanz & Rimer, 2005). The theory offers an understanding of the three way interrelationship among personal, environmental and behavioral factors on health outcomes (Bandura & Jourden, 1991; Glanz & Rimer, 2005). The Social Cognitive Theory is the conceptual framework on which this project was grounded. The application is discussed below and is illustrated in Figure 2. According to SCT, behavioral changes are the result of observational learning, where, a person learns and continue a behavior through the observation of others (Bandura, 1986; Glanz & Rimer, 2005). The theory postulates that the behavioral change is the result of constant interaction between environmental and personal factors (Bandura & Jourden, 1991). Environmental factors include the individual's physical environment, reinforcement, and observational learning (Bandura & Jourden, 1991).
Observational learning is the process of acquiring knowledge by watching someone else, that is, a model performs the behavior (Bandura & Jourden, 1991; Dewar et al., 2013). The consequences that result from a particular behavior act as reinforcements. These reinforcements may be translated in three facets: perceived consequences, self-reinforcement and vicarious reinforcement conveyed by observed benefit to others (Dewar et al., 2013). An individual may be motivated by observation to either abhor or perform a behavior frequently based on the perceived or known external consequences, such as punishment by law (Brown et al., 2013). Self-reinforcement is stimulated by the individual's own belief about the behavior (Brown et al., 2013; Clark et al., 2014).

Personal factors consist of outcome expectations, outcome expectancies, and efficacy expectations (Bandura, 1997; Brown et al., 2013; Nokeset al., 2012). Outcome expectation refers to what the individual hope to achieve in participating in a particular behavior while the expectancy refers to the advantages of those outcomes (Brown et al., 2013). Efficacy expectations or self-efficacy addresses the individual's perception of his ability to perform a behavior (Nokeset al., 2012). The more confident the individual is, the more likely he or she will be to perform the behavior (Nokeset al., 2012).

The constructs related to behavior include self-observation, self-judgment, and self-reaction (Bandura & Jourden, 1991; Nokeset al., 2012). In self observation the individual makes an effort to reduce behaviors that produce negative outcomes and is more likely to increase behaviors that produce positive outcomes (Bandura & Jourden, 1991). If a client receives positive feedback from others regarding his/her attempts at adherence. The more likely he/she is to keep doing those behaviors. Self-judgment
refers to the individual's perception of the behavior whether it is "good" or "bad" opting to repeat the behaviors that are deemed to be good (Bandura & Jourden, 1991; Clark & Zimmerman 2014; Nokeset al., 2012). Self-reaction is the resultant incentive or penalty the individual inflicts on himself from engaging in a particular behavior (Clark & Zimmerman, 2014). Self confidence is increased with incentives and leads to repeating desirable behavior. On the contrary, penalties lead to avoidance of the behavior and decrease self-worth (Clark & Zimmerman, 2014; Nokeset al., 2012). Figure 1 is a representation of the SCT as interpreted from Glanz and Rimer (2005).

*Figure 1.* Diagrammatic Representation of the Social Cognitive Theory. Adapted from Bandura & Jourden, 1991; Clark & Zimmerman 2014.
The Logic Model

The logic model was used to guide the processes in this project. The model is a successful tool frequently used in program development and evaluation to demonstrate expected performance and outcomes (CDC; 1999; Kellogg Foundation, 2004; Sundra, Scherer, & Anderson; 2003). The model identifies available resources as inputs. The output refers to the participants and activities employed to meet the program objectives (CDC; 1999; Sundra et al., 2003). Expected program outcomes are reflected through the short term, medium, and long term. The logic model is effective, in that, it provides a clear picture for each person involved in the program to assess progress. People are aware of the expectations and readily identify whether or not these are being met (CDC; 1999; Sundra et al., 2003). Figure 2 is a demonstration of how the logic model was applied to this project (CDC; 1999; Kellogg Foundation, 2004; Sundra et al., 2003).

Figure 2. Logic Model Applied to Project. Adapted from CDC, 1999; Kellogg Foundation, 2004; Sundra, Scherer, & Anderson; 2003.
Summary

HIV/AIDS is a chronic disease without any known cure (CDC, 2015; Sharp & Hahn, 2011). Since its discovery in the early 1980s, over one million people have been infected worldwide (CDC, 2015; Sharp & Hahn, 2011; Vatanoglu & Ataman; 2011). Clients who are consistently adherent to treatment regimens have been shown to maintain CD4 count within normal limits (Demmer, 2003; Lester et al., 2010; Remien et al., 2003; Sharp & Hahn, 2011). Health care providers offered reflections regarding the treatment adherence behaviors of clients who were in the clinical latency phase of the disease.

There were two primary research questions: What are the main factors that contribute to non-adherence to HIV treatment regimen? and How may health care providers increase the rate of HIV treatment adherence among people living with HIV/AIDS? Two theories were identified which were related to health promotion. The SCT and the logic model were used to guide and interpret how providers in this study viewed the actions of and their work with clients. The SCT offers an understanding of the interactions between people and their environment along with behavioral factors that influence health outcomes (Bandura & Jourden, 1991; Glanz & Rimer, 2005). The logic model was the tool used to evaluate the process of the project (CDC; 1999; Sundra et al., 2003). The information gathered through the interview of the health care providers helped to identify themes related to HIV treatment adherence.
REVIEW OF LITERATURE

Search Methods

The online data bases used to extract research publications for this literature review includes: primary sources identified from the Cumulative Index to Nursing and Allied Health Literature Plus with Full Text (CINAHL), Google Scholar, Pub Med, PsycInfo databases, PubMed, Cochrane Library and government agencies website. Key search terms included: HIV AIDS treatment clinics, factors affecting HIV treatment adherence, HIV management approaches, Medical care coordination, Ryan White, HIV treatment incentives, HIV adherence improvement strategies, HIV peer mentoring, HIV stigma, HIV treatment high risk, viral load and adherence, mental illness and substance abuse, HIV treatment adherence and self-efficacy, HIV and homelessness and social support. The search was initially made to include the historic years of HIV onset then restricted to include more recent reports. Studies that were reported in languages other than English and those older than fifteen years were excluded. Other factors which were not initially included in the search criteria but were identified within the studies reviewed as contributors to non-adherence to HIV treatment were explored for relevance.

Search Results

Based on the inclusion and exclusion criteria, over 52 research articles were reviewed. Studies relating to the social cognitive theory were included regardless of the date published due to their relevance in providing plausible information. The types of the articles ranged from research proposals, research presentations, program evaluation, case studies, meta analysis and literature reviews to that of high quality systematic reviews of controlled trials. Thus, the quality of the articles selected varied and included
quantitative and qualitative survey studies of varying levels. This project focuses on addressing level one to level three concerns regarding HIV treatment non-adherence.

**Overview**

The treatment and containment of HIV infection remains a major global public health concern since its emergence in the early 1980s (Chattu, 2015; Vatanoglu & Ataman; 2011). There have been countless studies which have attempted to understand the nature of the disease and its impact on individuals and society (Valdiserri, 2011; Vatanoglu & Ataman; 2011). Several studies have explored the depth of knowledge, attitudes and practices of people living with HIV/AIDS (PLWHA) as well as their care providers and their responsiveness to treatment options (Berkman, Garcia, Munoz-Laboy, Paiva, & Parker, 2005; Rogers, Corcoran, Hamdallah, & Little, 2012; Sison et al., 2013). Several HIV treatment centers have been established and have proved to be beneficial in improving the quality of life (QoL) along with increasing life expectancy of PLWHA (Berkman, Garcia, Hamdallah, & Little, 2012; Mills et al., 2011; Munoz-Laboy, Paiva, & Parker, 2005; Rogers, Corcoran, Sharp, & Hahn, 2011). This literature review focused on three major areas related to HIV treatment: (a) barriers and facilitators to HIV treatment adherence (b) care approaches and perception of HIV treatment providers and (c) a discussion of the Social Cognitive Theory (SCT) as it applies to this project.

**Barriers and Facilitators to HIV Treatment Adherence**

Fear and stigma have been long standing barriers for seeking and continuing treatment for PLWHA (Ramirez-Valles et al., 2013). Challenges to adherence have often been related to the accessibility and demands of the treatment regimen, lack of social support, substance abuse and mental illness (Remien et al., 2003). Investigations on the
influence of race, gender, and age on adherence are equivocal (Penn et al., 2011). In one study comorbidity and race did not influence commencing and sustaining anti-retroviral treatment (ART). Researchers Abara et al. found that there was no significant difference between HIV treatment adherence and race (Abara et al., 2014). However, they reported that older people living with HIV/AIDS (PLWHA) were more likely to seek and adhere to their treatment regimen if they had other comorbidities such as hypertension (Abara et al., 2014). Wilson, Sikkema, and Ranby (2014) determined that male gender played a role in substance abuse and ART adherence. It has not been determined if this finding is related in proportion to demography and life experiences of the clients enrolled in treatment (Wilson et al., 2014).

In a cross-sectional study conducted in Cuba, Arogones et al. (2011) assessed the predictive factors and levels of treatment adherence in 847 persons with HIV/AIDS. The study participants were receiving antiretroviral therapy greater than 6 months. Adherence was measured by three factors: client self report, clinician assessment, and lab work. All three measures had to correspond in adherence for improvement to be noted (Arogones et al., 2011). The study found that 70.6% of the participants were adherent. However, there were no significant differences found between adherent participants and gender, region of residence, treatment setting, and time of diagnosis or years in treatment (Arogones et al., 2011). Adherence was noted to decrease significantly in relation to an increase in the number of tablets and doses required to be taken per day (Arogones et al., 2011). Self-efficacy and commitment to treatment were major factors enhancing adherence. One limitation of this study was that adherence was self reported (Arogones et al., 2011).
In a qualitative study conducted by Remien et al. (2003), adherence was noted to be influenced by multiple complex factors. This multifactor phenomena changed over time. The researchers identified ten broad domains that influenced adherence: (1) belief and trust in the antiretroviral medicine and health care providers; (2) experience of side effects and concerns about toxicity; (3) self monitoring and taking personal control; (4) role of "alternative" or "complementary" therapies; (5) role of past and current substance use; (6) regimen demands and planning; (7) priorities, competing concerns, and mood states; (8) social supports; (9) future orientation; and (10) ambivalence. These factors may be categorized into four main themes: patient factors; medication characteristics; interpersonal characteristics/ social supports and the general health care system (Remien et al., 2003).

**Mental Health and Substance Abuse**

Treatment adherence is difficult when patients have identified mental health issues as well as substance abuse problems (Blashill, Perry, & Safren, 2011). Several psychosocial issues affect the clients and impacts non-adherence (Dale et al., 2014; Wilson et al., 2014). These include post traumatic stress disorder (PTSD), anxiety disorders and body image dissatisfaction which may be related to abuse (Dale et al., 2014; Wilson et al., 2014). It is noted that over 33% of PLWHA have history of childhood sexual abuse (CSA; Wilson et al., 2014). History of childhood or other sexual abuse and trauma have several psychological consequences (Dale et al., 2014; Wilson et al., 2014). This factor is often less explored as contributing to treatment non-adherence and poor health outcomes (Dale et al., 2014; Wilson, Sikkema, & Ranby, 2014). Substance abuse use is often part of the sequel to CSA and PTSD (Dale et al., 2014;
Wilson et al., 2014). Research findings indicate that alcohol use is higher among PLWHA than in the general population (Hendershot, Stoner, Pantalone, & Simoni, 2009). Alcohol and substance abuse result in neuropsychological impairment, which often lead to poor decision making (Hendershot et al., 2009; Rothlind et al., 2005).

An exploratory study examining treatment adherence among HIV-infected individuals at four AIDS service organizations in New York found that non drug users had statistically significant higher emotional health scores than illegal drug users (Demmer, 2003). Non drug users were also more likely to be on schedule with their medication than drug users (28.6% vs 4.8%). The ripple effect of trauma, substance abuse and mental illness has been a longstanding barrier to HIV treatment adherence (Blashill, 2011; Dale et al., 2014; Hendershot et al., 2009; Rothlind et al., 2005; Wilson et al., 2014). Trauma and drug abuse history should be considered when reviewing interventions to improve HIV treatment adherence (Blashill, 2011; Dale et al., 2014; Hendershot et al., 2009; Rothlind et al., 2005; Wilson et al., 2014).

**Homelessness and Social Factors**

A client’s level of social support often will facilitate adherence to treatment regimen (Blashill et al., 2011). Treatment adherence is also impacted by the client’s living situation (Palepu, Milloy, Kerr, Zhang, & Wood, 2011). Clients who are homeless demonstrate greater challenges adhering to their HIV treatment (Surratt, Kurtz, Levi-Minzi, & Chen, 2015). Individuals who are homeless tend to have greater challenges accessing health care and are at higher risk for poor health outcomes (Bralock et al., 2011). Furthermore, homeless persons living with HIV have been found to be less likely to access and receive optimal regular HIV care (Surratt et al., 2015).
Healthcare Providers

It is evident that communication and culture influence how clients relate to treatment providers (Jones, Cook, Rodriguez & Waldrop-Valverde, 2013; Penn et al., 2011). This relationship may often have an effect on client's adherence to treatment regimen (Jones et al., 2013; Penn et al., 2011). In addition to the typical language barriers that may exist between clients and healthcare providers, there was a frequent report in studies regarding the difficulty clients had in understanding terminology associated with instructions related to testing and treatment regimens (Penn et al., 2011; Saberi et al., 2012). Aragonés and colleagues determined that client's misunderstanding of their care providers instructions and actions contributed to poor adherence rates (Aragonés, et al., 2011). Another factor associated with culture was that of the challenges some clients face in disclosing to healthcare providers, information they deem sensitive (Castro et al., 2015; Chattu, 2015; Costa, et al., 2012; Penn et al., 2011; Remien et al., 2003).

Care Approaches and Perception of HIV Treatment Providers

Several studies investigated strategies utilized to help improve clients adherence to their ART and explored reasons for non-adherence (Palepu et al., 2011; Surratt et al., 2015) Approaches included use of adherence counselors (AC), motivational interviews, care coordination, mobile text message and microelectronic monitors (MEMS), to name a few. The literature suggests that adherence rates vary based on the interventions with proven successful outcomes (Castro et al., 2015; Laws et al., 2012; Scheid, 2007). For example, the use of adherence counselors increased treatment adherence among 57% of the participants in a North Carolina study over a six-month follow up period and 73%
over a 12-month period (Scheid, 2007). However, sustainability was a challenge. The study postulated that in order to improve treatment adherence, ongoing and long-term follow-up is needed to change an individual's belief system and reduce the complex barriers that influence negative attitudes towards HIV treatment (Scheid, 2007). An evaluation of pharmacist education and counseling introduced at three pharmacy-driven clinics was conducted. Researchers reported that increase in adherence rates was observed in all studies compared to control groups (Seden, Back, & Khoo, 2010). Also, the interventions increased clinical outcomes. Clinical outcome was measured by assessing the rates of hospitalization, opportunistic infections and viral count (Seden et al., 2010).

A systematic review conducted by Saberi et al. (2012) also substantiate the relationship between interventions by pharmacy personnel and improvement in ART adherence. It is recommended that more is done to increase the involvement of pharmacy in the coordination of care for HIV positive clients. (Saberi et al., 2012; Seden et al., 2010).

Summary

Findings in the literature support the key concepts frequently identified as influencing clients behavior towards HIV treatment (Chattu, 2015; Costa et al., 2012; Remien et al., 2003). These factors may be related to clients personal issues, social and environmental influences (Arogones et al., 2011; Penn et al., 2011; Scheid, 2007). These may further be categorized as barriers and facilitators to treatment adherence. Treatment adherence is noted to be negatively affected by mental illness, homelessness, substance abuse, history of trauma and abuse, lack of social support and education, stigma, poor self
esteem, unemployment, and fragmented health care. Conversely, reports of improved and successful treatment adherence were attributed to interventions that involved the synergy of support in a positive social environment. Clients adherence outcomes improved when they had positive encounters with their environment and the health care system (da Costa et al., 2012; Demmer, 2003; Scheid, 2007). Interventions including providing recourses, motivation, and support from the health care providers were also positive influences towards treatment adherence (da Costa et al., 2012; Demmer, 2003; Lester et al., 2011; Palepu et al., 2011; Penn et al., 2011; Scheid 2007; Surratt et al., 2015).

Numerous studies in the literature examine the behaviors and outcomes of HIV treatment adherence among PLWHA (da Costa et al., 2012; Demmer, 2003; Palepu et al., 2011; Penn et al., 2011; Scheid, 2007; Surratt et al., 2015). In many instances treatment adherence was self reported by clients and left a void as to the accuracy of the findings (Arogones et al., 2011; Demmer, 2003; Enriquez, O’Connor, & McKinsey, 2003; Remien et al., 2003; Scheid, 2007). Examining the CD4 count of the clients seemed to be the most validating predictor of medication adherence (Lester et al., 2010; Scheid, 2007; Surratt et al., 2015). More studies should be conducted to ascertain the health care providers perception towards clients treatment adherence behaviors (Surratt et al., 2015).
METHODS

The overall goal of this project was to identify strategies to improve the treatment adherence rate of high risk clients in an ethnically diverse urban HIV treatment clinic by evaluating clinic processes and developing recommendations for their improvement. A descriptive qualitative study approach was used in which semi-structured interviews of health care providers were completed. The project was based on the theoretical framework of the social cognitive theory and the logic model to ascertain the phenomenon of the essence of adherence. The concepts or themes were assessed as they related to personal and environmental factors, which contributed to the client’s behavior. Personal and environmental factors identified included mental health issues, substance abuse, social support, self-efficacy and living arrangements. Other factors related to barriers or facilitators to adherence were discussed based upon relevancy to the project.

The client’s adherence to HIV treatment as described by healthcare providers was the concept of interest. The primary clinic used specific criterion to classify clients as high risk. The criterion used in the present project to assess adherence of the clients served by the providers in the study were described in the literature review. The criteria included items such as viral load more than 400, missed follow up appointments, history of substance abuse, incarceration and diagnosis of sexually transmitted infection (STI) within the past six months. These clients were referred to the MCC team for assessment and follow up. This project reviewed the process of interaction and interventions as perceived by the MCC and high risk clients' care teams at select treatment clinics.
Protection of Human Rights

Faculty support and Institutional Review Board (IRB) approval was obtained from the California State University, Long Beach (CSULB); (Appendix A and B). A letter of introduction to the project was sent to the clinics (Appendix C), and permission to conduct the interviews was obtained from all three agency nurse managers prior to the clinic providers’ recruitment for the interview sessions (Appendix D). After agency approval was obtained, a letter soliciting project participants was distributed (Appendix E). Providers agreeing to participate in the project were asked to sign an informed written consent form (Appendix F). The consent acknowledged their voluntary participation and addressed the tape recording of the session. Clinic patients did not participate in this project and, as requested, healthcare participants did not identify patients by name or provide any other identifying patient information during the course of the interviews. The project was conducted within the given timeframe approved by CSULB IRB.

Project Description

The phenomenon of interest for this program evaluation project is adherence, which is best studied using a phenomenological qualitative research design. Semi-structured interviews were conducted to secure the necessary information linked to facilitators and barriers to treatment adherence in high risk HIV patients in selected treatment centers. Themes as associated with adherence and non-adherence were developed and findings compared among the treatment settings to complete a gap analysis. Recommendations from this evaluation will be presented to the project clinic upon completion of this Doctor of Nursing Practice project. Case studies of three HIV

treatment settings using semi-structured interviews with scripted open-ended questions were utilized to collect data. The rate of patient non-adherence, case management approaches, resources that promote adherence, and barriers to adherence (i.e., the lack of specific resources) were assessed. After having reached saturation of information related to these factors, themes were identified and discussed in the results section.

**Setting and Sample**

Three HIV-treatments clinics were selected for this study. Clinic A is the primary project clinic; and B and C were selected to serve as resource centers for this project. These two healthcare settings (B and C) were regarded as premier HIV-treatment clinics that provided quality healthcare for HIV positive clients, many of whom were considered high risk for non-adherence to their HIV treatment. The primary project clinic, also an exemplary health center, is seeking to improve the HIV treatment adherence rate among their clients. Clinics B and C, were also chosen in order to compare the practices they use to promote treatment adherence with the current practices used at the primary project clinic (Clinic A). A practicing clinical nurse specialist administrator identified one of the treatment clinics (Clinic B) as being similar in the practice to the project clinic. The other HIV treatment clinic (Clinic C), also similar in practice to clinic A, was selected based upon a reference from a Coordinator in the Doctor of Nursing Program. The number of clients seen monthly and the rate of adherence at each clinic were identified. Clinics A and B were primarily Ryan White funded clinics, explained earlier. All three clinics were located on the campus of an acute care medical center. The participants for this project were selected using a convenient sampling method. The clinic manager identified possible care providers who attended to the high risk client population at each
clinic. These care providers were then contacted by the investigator to solicit their participation. The sample consisted of the care providers who were nurse practitioners, social workers, nurse case managers, pharmacy technician and case workers. The care providers at each of the three clinics were interviewed individually at their clinic. Interviews were conducted at a time convenient to the providers in a private room. Semi-structured interviews were conducted and tape recorded following written consent. The interviews were transcribed by the project investigator with the assistance from the project co-chair and identified research experts.

Project Design

Upon IRB approval, the project began with the researcher contacting clinics to gain approval to conduct the project at their sites. An approval letter was obtained from clinic administrator or the nurse manager at each clinic. Clinic administrators/managers identified the care providers who worked with high risk clients. The clinic administrator or manager arranged meetings of the investigator with the care providers for introduction, to discuss the nature of the project and explanation of consent form. The investigator then left the staff to privately review and complete consent forms. Care providers who consented were the participants selected for interview. The interviews were conducted at the three clinic sites, two in southern California and one in northern California, at a time that was convenient for each care provider. The number of interviews was based upon the number of care providers who consented to participate in the project.

The analysis phase of the project was projected to continue through December 31, 2015; however, this continued to February 2016. Procedures for the project were as follows:
1. Reviewed literature and client assessment forms used by each of the three clinics to determine patient needs for services or resources

2. Developed open ended questions and have questions reviewed by research experts

3. Submitted IRB application

4. Contacted clinic administrators and explained purpose and nature of project. Identified the care providers of the high risk clients explained and obtain their consent to participate

5. Conducted semi-structured interviews of participating care providers

6. Conducted review of care provider interviews, develop themes and identify gaps

7. Completed analysis and will arrange a time to provide recommendations to clinics.

The first phase of the project involved a review of the patient assessment form. The investigator then identified categories of needs assessed in this form to use as inclusion points in the focused interview discussions. Next, the investigator asked for a listing of resources and services available to their clients and assessed the current interventions to meet the needs of this special group of clients and resources available.

The second phase involved the development of the topics and open-ended interview and demographic questions. The interview questions were based upon the research findings reported in the review of literature, from the DHHS needs assessment form, and from available resources/services within the community. This helped in the structuring of the topics of discussion for the interviews. After the development of the
focused interview questions, they were shared with a panel of experts to evaluate the appropriateness of the content, and sequencing of the questions. The panel of experts included researchers from the Southern California State University DNP Consortium and from the University of California, San Francisco. The panel assisted in reviewing the interview questions and provided guidance for the development of themes based upon the project questions.

The third phase utilized semi-structured interviews with professionals in two established HIV centers with populations similar to that of the project clinic. This was to investigate the barriers and facilitators of HIV treatment compliance that other clinic professionals identified in their client population and the strategies they employed to improve HIV treatment adherence rates. Semi-structured interviews with providers were conducted to identify strengths, weaknesses, opportunities and threats to treatment program adherence. Open ended questions, reviewed by experts, were used to ascertain how the clinics prioritize the needs identified and the resources they provided to the clients. The interview was conducted in a private room at the convenience of the provider and took approximately 40 minutes to complete.

The fourth phase focused on the analysis of the narrative data. The social cognitive theory (SCT), described earlier, was used as an overarching theory to categorize and evaluate factors that the providers identified in their case management activities as contributing to treatment adherence and continuance of care for high risk HIV positive clients. The logic model was used to delineate the process of the project. The fifth phase involved a gap analysis of what interventions are in place at the project’s primary center and what additional interventions are needed as identified in the focused
interviews. At the conclusion, the primary clinic will be provided with the findings and recommendations of this evaluation project.

Review of the blank client needs assessment forms used by the project clinic and the other two HIV treatment clinics was conducted again at the end of the interviews and after narrative analysis. This was to identify how a client's profile was obtained and what adjustments were necessary to the current form and the processes used at the primary clinic in their attempts to identify facilitators and barriers to treatment adherence. This form was reviewed to establish how information about the client regarding their social, health needs, and access to healthcare is assessed. Review of available resources to high risk HIV positive clients at the project clinic and the other HIV treatment clinics was done to determine what resources, or processes if any, should be added, so that the primary clinic may improve their adherence rates.

**Demographic Questions**

Questions were developed to gather descriptive information regarding the participants' personal data (Appendix G). Information obtained included the participants' age, gender, race, and sexual orientation. Participants were also asked to provide non-personal identifying data regarding the demography of the clients enrolled in the treatment program. This background information helped in understanding the participants in context. A future study may be one that investigates if and how the background of health care providers influence their role and perceptions of the HIV-positive clients they treat.
Interview Questions

The focus of the questions was on client’s adherence or non-adherence to their HIV treatment regimen (Appendix H). The care providers were asked questions such as “What tool do you use to assess the clients enrolled in this treatment program? Tell me how you use this assessment tool and what is helpful about the tool related to capturing facilitators and barriers to treatment adherence? What do you think is missing, if anything, in this tool in its ability to provide a comprehensive or holistic picture of your client?” Questions related to resources asked care providers: “Tell me about how your high risk clients become involved in using your resources or your perceptions of why they are reluctant to access these resources? How do you get your clients to use resources? Is funding a factor in non-adherence? If yes, what are some of the areas that may need additional funding to help increase adherence? What seems to be the top two to three incentives that you offer your clients that seem to work to best to help them adhere to their treatment? How may your clinic be more targeted in the allocation of funds?” Questions relating to services and support to the client in the community included: “What in your experience has been the best approach to enhance adherence in the high risk client? What just doesn’t work for your client? How are priorities set for your clients? How does funding or policy direct your care?” Transcriptions were made of all interviews and the identification of themes was conducted from the project questions.

Analysis Strategies

Qualitative Data Analysis of transcribed interviews was conducted with the use of Dedoose 7.0.16 as well as the assistance of research experts for validation of the findings.
Dedoose is an electronic software program, which facilitates the interpretation of qualitative information. The Illustrative method was the strategy used to develop categories from theoretical concepts. The categories are derived from empirical examples and textual excerpts. The excerpts are then compared and matched across interviews (Neuman, 2011). Matches within categories help to narrow possible explanations for the phenomena of interest, which aligns with the theoretical framework (Neuman, 2011).

Three research experts provided consultation in the analysis of the narrative data. Expert A was a psychological research expert with a PhD who was faculty at an institution of higher learning. He has experience using several qualitative research analysis programs including Dedoose. Expert B was a school psychologist with an Ed.D. in Educational Leadership with extensive experience in conducting research related to evaluation and counseling. Expert C was a faculty member at an institution of higher learning with a DPA and had a number of years of experience teaching research methodology. Collectively the panel has 16 publications among them (Appendix I).

The project investigator along with the analysis experts developed the themes and categories for the project using the constructs of the SCT model. The process began by uploading the transcribed interviews into the Dedoose software program using the predetermined coding structure. The excerpts were then organized and identified by clinic sites. The number of excerpts gathered from each participant was presented (Figure 3). The process provided an overview for generating the themes as well as a means of comparison across interviewees at each clinic site. In general, there was consistency in the number of excerpts pulled from each interview. This process was effective for gathering in depth information for comparison among the clinics.
Figure 3. Number of excerpts by clinic type and participant.

Excerpts from interviews were sorted by code and then identified as a personal or an environmental factor related to treatment non-adherence. Code categories provided the structure for the development of the themes that emerged from the interviews. The codes formed a categorization tree, which provided a visual structure to view the development of the themes (Figure 4). Comparisons and contrasts were made among the codes to determine the themes that emerged from the interviews. The third expert in the analysis of this data reviewed the SCT and agreed that using the constructs of the SCT to develop the codes provided a valid method for the determination of themes. After themes emerged, a consensus was determined using the following process. Each expert reviewed the data individually then provided their interpretation and recommendation for the presentation of the themes along with the supporting narratives of the project participants.
<table>
<thead>
<tr>
<th>Code</th>
<th>Code Definition or Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Behavioral Factor</strong></td>
<td><strong>Adherence/Non-adherence</strong></td>
</tr>
<tr>
<td>Percent of Non-Adherent Clients</td>
<td></td>
</tr>
<tr>
<td><strong>Client Personal Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Client Gender</td>
<td></td>
</tr>
<tr>
<td>Employment Status/Homelessness</td>
<td></td>
</tr>
<tr>
<td>Mental Health Status</td>
<td></td>
</tr>
<tr>
<td>Client Age</td>
<td></td>
</tr>
<tr>
<td>Client Race</td>
<td></td>
</tr>
<tr>
<td>Client Beliefs</td>
<td><strong>Belief in ability to adhere</strong></td>
</tr>
<tr>
<td>Client Substance Abuse</td>
<td></td>
</tr>
<tr>
<td><strong>Client Non-adherence</strong></td>
<td></td>
</tr>
<tr>
<td>Challenges Related to Non-adherent Clients</td>
<td></td>
</tr>
<tr>
<td>Your Feelings towards</td>
<td></td>
</tr>
<tr>
<td>Non-adherent Clients</td>
<td></td>
</tr>
<tr>
<td><strong>Environmental Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Number of HIV Positive Clients</td>
<td></td>
</tr>
<tr>
<td>At Clinic</td>
<td></td>
</tr>
<tr>
<td>Seen by the Staff Member/Interviewee per Day</td>
<td></td>
</tr>
<tr>
<td>Health Insurance</td>
<td><strong>Do clients have disability or health insurance?</strong></td>
</tr>
<tr>
<td><strong>Physical and Psychosocial Needs Assessment</strong></td>
<td></td>
</tr>
<tr>
<td>Helpfulness of Assessment</td>
<td></td>
</tr>
<tr>
<td>Missing Elements in the Assessment Protocol</td>
<td></td>
</tr>
<tr>
<td><strong>Resources for Clients</strong></td>
<td></td>
</tr>
<tr>
<td>How Clients Access Resources</td>
<td></td>
</tr>
<tr>
<td>How Staff Helps Clients Get Resources</td>
<td></td>
</tr>
<tr>
<td>Client Reluctance</td>
<td><strong>Why are clients reluctant to use resources?</strong></td>
</tr>
<tr>
<td><strong>Beliefs about Causes Impacting Client Ability to Adhere</strong></td>
<td></td>
</tr>
<tr>
<td>Clinic Funding</td>
<td></td>
</tr>
<tr>
<td>How Funding Directs Your Care</td>
<td></td>
</tr>
<tr>
<td>Areas to Fund that will help Client Adherence</td>
<td></td>
</tr>
<tr>
<td>Top Incentives Believed to Help Clients Adhere</td>
<td></td>
</tr>
<tr>
<td><strong>Services and Support to Clients</strong></td>
<td></td>
</tr>
<tr>
<td>Priorities for Client Treatment Plans</td>
<td></td>
</tr>
<tr>
<td>Facilitators of Adherence</td>
<td></td>
</tr>
<tr>
<td>Most effective approaches</td>
<td></td>
</tr>
<tr>
<td>Least effective approaches</td>
<td></td>
</tr>
<tr>
<td>Clients' view of staff dedication</td>
<td></td>
</tr>
<tr>
<td>Things staff and clinic do for welcoming atmosphere</td>
<td></td>
</tr>
<tr>
<td>Race/ethnicity issues</td>
<td></td>
</tr>
<tr>
<td>Gender issues</td>
<td></td>
</tr>
<tr>
<td>Age issues</td>
<td></td>
</tr>
<tr>
<td>Sexual orientation issues</td>
<td></td>
</tr>
</tbody>
</table>

*Figure 4.* Code categories and descriptions of excerpts from participant's interviews.
All themes and narratives from the expert review panel were included into one document labeled as preliminary findings. The project investigator shared the preliminary findings in meetings with each expert. Once again the SCT was reviewed, along with the codes and narratives. There was discussion regarding the adherence rates of each clinic since participants provided this information as part of the interview process. Thus, a general consensus was made to accept the average adherence rate as calculated from the reported narratives.
RESULTS

Twelve providers consented to participate in the project interviews. One provider did not consent to recording of the interview, thus notes were taken to memorialize the information. Providers were categorized based on clinic location. There were four providers from each clinic. The mean age of the providers was 42.6 years. There were four males and eight females. The mean age among males was 49.7 and it was 39.4 for females. There were no Native Americans, however, the participants were of diverse ethnic backgrounds. There were 4 Hispanics, 3 African American, 2 Asian/Pacific Islander, 2 White, and 1 was of mixed heritage. Three participants identified as Gay/Lesbian/Homosexual and one as bisexual. The remaining eight identified as heterosexual. The characteristics of the participants are summarized in Table 1. All, except one participant, had a college degree (Figure 5).
Table: 1

*Participant Provider Demography*

<table>
<thead>
<tr>
<th>Provider Demographics (n = 12)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
</tr>
<tr>
<td>Mean Age</td>
<td>42.6yrs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian/Pacific Islander</td>
<td>2</td>
</tr>
<tr>
<td>Black/African American</td>
<td>3</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>4</td>
</tr>
<tr>
<td>Native American/American Indian</td>
<td>-</td>
</tr>
<tr>
<td>White/Caucasian (non-Hispanic)</td>
<td>2</td>
</tr>
<tr>
<td>Other Ethnicity-mixed</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Educational Level</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2 years of College/Associates Degree/Technical School</td>
<td>1</td>
</tr>
<tr>
<td>College or University(B.A or B.S.)</td>
<td>3</td>
</tr>
<tr>
<td>Graduate Degree (Master's)</td>
<td>7</td>
</tr>
<tr>
<td>Some College</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sexual Orientation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gay/ Lesbian/Homosexual</td>
<td>3</td>
</tr>
<tr>
<td>Straight/Heterosexual</td>
<td>8</td>
</tr>
<tr>
<td>Bisexual</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
</tr>
</tbody>
</table>

*Figure 5. Participants academic degrees.*
Participants Roles and Clients Served Daily

The 12 participating providers in their various described the demography of the clients they served as being diverse. On average, the participants reported servicing approximately nine clients per day. However, one provider stated; “anywhere from about 28 patients a day depending on the basis of their clinic appointments.” Another provider was specific in making the distinction regarding the number of clients served daily: “On a daily average, face to face, I see probably 10-15 clients. On the phone, on a daily basis, I speak with (I'd say) 15-20 clients. Through email, I interface with probably about 20 clients a day.”

![Bar chart](image)

*Figure 6. Number of project participants by role.*
The rate of non-adherence to treatment was calculated by averaging the numbers reported by the participating providers at each site during interview. In clinic A, one participating provider reported a non-adherence rate of 5% but expressed great uncertainty. Therefore, this was excluded from the calculation. Clinic A had reported that 33.3% of their clients were non-adherent at the beginning of 2015. The interviews were conducted in November 2015, at which time the reported non-adherence rate was 28%. Clinic B and Clinic C reported similar non-adherence rate, differing only by 1% (Figure 7). These numbers represent a variation in treatment adherence from partial to complete non-adherence. The reported improvement in adherence rate at Clinic A may have been related to the implementation of a second MCC team earlier in the year. However, this supposition has to be validated by further research.

Figure 7. Clinic's reported treatment non-adherence rate.
Usefulness of Assessment Tool

All three clinic sites were associated with and located at an acute care medical center. Sites A and B report similar treatment models and utilize the Department of Public Health assessment protocol (Appendix J). Whereas, Clinic C created its own assessment tool. A participant from Clinic B reported: "All the MCC teams use the same tool. It doesn’t matter which clinic. And we all use the same program, Casewatch.”

"MCC has a very thorough assessment. The assessment is actually a two stage assessment. There is a screener process where we screen our patients, basically just looking at their T cells, their viral load, their history of treatment. Any past STI’s or hospitalization and substance use. And based on that screener, they will either meet enrollment to MCC or not. And if they do meet enrollment criteria, then we begin the other assessment process, which is like a 90-minute assessment conducted by the social worker and the nurse together. That assessment is very thorough for any medical issues and then also psychological issues.”

All the providers expressed satisfaction with the assessment tool used at their facility. They felt that it was very comprehensive and painted a good picture of the client's status. “And it’s scored when you’re finished putting everything into Casewatch, it’ll tell us if understanding of HIV needs to be addressed, or their financial needs to be addressed.” “It’s put into a program called Casewatch that they also design to find out the severity of the patient—it gives us an acuity. And that tells us how often we have to work with this patient.”

Although 100% of the providers reported that the assessment tool was beneficial, more than half of them felt that there was a gap regarding some crucial client
information. “There’s one question in there about medication adherence and I think we could probably add a little bit more.”

The following excerpt summarized another participant's opinion.

It’s a good assessment tool; it’s not perfect. I mean, it’s a good assessment tool because it does have all the basic questions we need to know of the patient. But most of the time, I feel…and I know that the social worker also has her concerns, because sometimes we know that when we assess this patient, this patient needs a lot of help. But once you put it on the computer, on the program, it tells us that this patient is self-managed, which means that they don’t need our help but we know that they do. So based on that program—the program doesn’t reflect the true picture of the patient.

The provider believed that the process should be reviewed with their input to capture a more holistic view of the client.

First of all, I think we need to have the people who designed these programs to maybe come and observe what we do so they can make the changes necessary and every once in a while come and check with us and say, “hey…do you think…what do you think about the program, do we need to make any changes? What do you like or why don’t you like this program, any changes?” You know, every once in a while because I think they designed it but once it’s put into effect in an actual setting with the clients, it’s totally different. They come here ever so often to evaluate the program but I feel like they’re just seeing it…they see it from a different perspective from us than how we deal with our clients. I’m not sure if I’m explaining it correctly.

Based on the provider's "human assessment" they know that the client needs help, however, the program does not recognize that need. An example was presented regarding addressing comorbidities:

A lot of our patients—yes, they have HIV, but they also have comorbidities that also affect their health status. But I was told I’m only taking care of the HIV part—who cares about the diabetes, who care about hypertension? As a nurse, I feel like I have the responsibility to also educate on those things which will eventually affect their life not directly on their HIV but their health. So I’ve been told we’re only taking care of the HIV part.
Consensus of the participants from Clinics A and B was that this assessment process was very comprehensive but lacked the capability to capture the clients who were "in between" the criterion it stipulated.

I think the one thing I would probably change about the questionnaire is that it doesn't allow for opened ended answers. It only gives you a list of answers and sometimes, certain questions, there should be an 'other' so that the person can respond more appropriately versus trying to make something fit into the answers that they give us.

Clinic C had developed their own psycho-social assessment template and reported it to be comprehensive, in that it included more open ended questions enabling them to identify unique patient's needs.

I think it's actually good. I mean I've used it as a tool; we have an intern and a peer advocate and a social work associate. So I've used it to just kind of standardize what it is we're all doing. But it's excellent. I think if you did the whole assessment it takes an hour. And people can be reassessed as needed. It's just finding that time, and often times people come in with a very specific request. It tends to be more practical if someone is self referring. They'll come asking for help with their insurance or housing or a referral for some practical need and then from there you kind of deal with their chief concern and then kind of open it up to more global.

An important factor discussed by a participant at Clinic C as missing from the assessment process was that related to the partners of PLWHA. Assessing the partner status and its relationship to treatment adherence is another area identified in this project as requiring further exploration and education.

Right, I think maybe another thing that we're not talking about enough with our HIV positive patients is the HIV status of their partners. Like we do some secondary prevention, prevention with positives, but we could be doing more with that. And I would like to see us more consistently at every visit asking are you having sex with HIV negative people? Do they know about PREP?
Barriers and Facilitators to Treatment Adherence

Results of the interviews identified the factors related to barriers and facilitators to HIV treatment adherence as perceived and assessed by the participating health care providers. The factors identified by the health care providers as contributing to treatment non-adherence were similar to those described in the SCT (Bandura & Jourden, 1991). Themes consistent with findings in the literature emerged from the interviews and were classified under three headings: Client or personal factors, Environmental factors and Healthcare Service/treatment factors. Similar to other research findings, participant providers identified a number of personal factors which interfered with and contributed to clients' non-adherence to HIV treatment.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Adherence Facilitators</th>
<th>Adherence Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1: Personal Factors</strong></td>
<td>Motivation &amp; will to live</td>
<td>Shame and Fear</td>
</tr>
<tr>
<td></td>
<td>Encouraged by positive health outcome: (CD4 Count)</td>
<td>Mental Health issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Substance Abuse</td>
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<td></td>
<td></td>
<td>Unemployment</td>
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<td></td>
<td></td>
<td>Homelessness</td>
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<td></td>
<td></td>
<td>New diagnosis</td>
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<td></td>
<td></td>
<td>Lack of education about the disease</td>
</tr>
<tr>
<td><strong>Theme 2: Environmental Factors</strong></td>
<td>Social support-Support groups</td>
<td>Stigma</td>
</tr>
<tr>
<td></td>
<td>Support from health care team</td>
<td>Medication cost</td>
</tr>
<tr>
<td></td>
<td>Care coordination</td>
<td>Under or uninsured</td>
</tr>
<tr>
<td></td>
<td>Trust in care provider</td>
<td>Lack of transportation</td>
</tr>
<tr>
<td></td>
<td>Welcoming healthcare atmosphere</td>
<td>Pill burden/other illness</td>
</tr>
<tr>
<td></td>
<td>Easy access to health care provider</td>
<td>Fragmented health care system</td>
</tr>
<tr>
<td></td>
<td>Clinic provided resources: transportation, food, housing assistance</td>
<td>Lack of diverse health providers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of support from friends and family</td>
</tr>
</tbody>
</table>

*Figure 8. Facilitators and barriers to treatment adherence.*
Personal factors identified by the participating providers included; Lack of support from friends and family, poverty, employment, education, homelessness and unmanaged mental health conditions. Clients health perception and perception in the ability to adhere to treatment were also contributing factors. Prior research revealed that these factors had varying levels of influence on treatment adherence (Blashill et al., 2011; Bralock et al., 2011; Palepu et al., 2011; Surratt et al., 2015). Age and gender were found not have as great an influence on treatment adherence as did mental health, homelessness and employment status (Abara et al., 2014; Penn et al., 2011; Remien et al., 2003; Wilson et al. (2014).

Participants stated that employment status interfered with HIV treatment adherence. Employment status was identified as both a personal and environmental factor in the SCT model. When a client was unemployed, they were more likely to be homeless as well. This interfered with treatment adherence in several ways. One reason being the client's primary focus on daily survival and not so much on their HIV treatment. A participant stated, “Patients are up against so much when they are homeless, when they have mental illness and they have an addiction. Just thinking about it from a hierarchy of needs perspective; if they are facing all of those challenges adhering to their HIV treatment might be a little bit lower down the list, than housing and food.”

Participants identified substance abuse as a personal factor influencing clients’ HIV treatment adherence. As a personal factor it interfered with their ability to take their medication, because it impaired their judgment. According to the participant, these clients were not able to focus on their treatment because they were more focused on obtaining their drugs. One participant said, “They are busy trying to get drugs, we have such an
epidemic of Meth use in the city, Meth more than any other drug seems to derail our patients from their treatment.” Providers stated that some clients did not adhere to their treatment because they reportedly sold their medication for money to treat their drug habit.

Environmental factors influencing non-adherence included social stigma, social support, accessibility to the clinic, and complexity of the treatment. In keeping with the assumptions of SCT, increasing the interaction from the care providers in portraying a caring attitude and reinforcing positive behaviors in the clients with incentives will enhance adherence to their HIV treatment regimen.

According to the SCT, individuals will change their behaviors as influenced by personal factors and interactions they have with their environment (Bandura & Jourden, 1991). The project participants explained that when working with clients who were non-adherent they would increase their interaction with those clients. The project participants believed that this level of support helped to portray a caring attitude. It allowed them to reinforce their client’s positive behaviors. They also offered incentives, which enhanced clients adherence to their HIV treatment regimen. Figure 9 illustrates how the SCT model was integrated into the project outcomes related to adherence to treatment among the clients at the selected HIV treatment clinics.
Participants Perceptions of Incentives for Treatment Adherence

Feelings towards non-adherent clients were generally positive and expressed in overall empathy. However, participants verbalized frustration and disappointments with some processes and systems as well as clients poor attitude. Participants offered an overwhelming response regarding incentives and reason why clients adhered to treatment. The top incentives were associated with meeting the clients basic needs of love and belonging, food and shelter as well as transportation. A number of providers cited that having an open door policy and just being available to talk to clients at anytime was beneficial.

One participant noted that the clients felt a sense of comfort and less apprehension when they are able to identify with their provider. "I'm kind of obviously gay. So it makes some of the gay patients in the waiting room feel, so I think it makes them feel a
little more relaxed to know that someone is. . . . I think they feel like if they can trust someone or that someone's looking out for them . . . that they have a relationship.”

Table 2 shows a summary of the top incentives that the providers perceived helped clients adhere to their treatment. A more thorough report is presented in Appendix K.
Table 2

Participants Perception of the Top Incentives for Client Treatment Adherence

<table>
<thead>
<tr>
<th>Incentives</th>
<th>Notable Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Love, Compassion &amp; Staff Support</td>
<td>“Make them feel loved and that we care about them genuinely and when (.......), does the intakes and meets the patients, he’s the one that meets them for the first time and he’ll introduce us to our future patient in case management so that they have a face to remember or that handshake, that hello.”</td>
</tr>
<tr>
<td></td>
<td>“I think that is a big incentive to being in the clinic, to have people that actually care about your well being, and want you to be healthy, and want you to benefit from all this research.”</td>
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<tr>
<td></td>
<td>“Our clinic is very family oriented so we try to treat every individual with respect and dignity.”</td>
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<tr>
<td></td>
<td>“So our patients are able to call and talk to our providers throughout the week. We do have ongoing follow up and our patients are called the day before their appointments to make sure they’re always in contact. So I’m not sure if that’s an incentive, but it’s definitely help.”</td>
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<tr>
<td></td>
<td>“Education ‘and’ the compassionate staff that’s working with you.”</td>
</tr>
<tr>
<td>Transportation</td>
<td>“So getting back and forth is a huge incentive, transportation is a huge incentive.”</td>
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<tr>
<td></td>
<td>“We give them tokens that they can get here by bus. Getting a disabled cap card, we link them so if they qualify for Access, we make sure they have the Access obligation so they can get it. We have binders and binders full of resources.”</td>
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<tr>
<td></td>
<td>“If transportation is an issue then we’ll provide them with a bus pass or tokens.”</td>
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<tr>
<td>Support Groups &amp; Self Motivation</td>
<td>“High risk group, since it’s hard to get them to make appointments we try to get them to come every Thursday for breakfast and then we try to schedule all their appointments on Thursday.”</td>
</tr>
<tr>
<td>Pharmacy Support</td>
<td>“One of the great things I think our providers do is help patients understand that this is how you're feeling today, but if you take the meds, if you're adhering with the meds and you do what we've outlined, this is how you will feel. This is what you can expect or should expect. When patients hear that you won't believe it, I think they're incentivized to take the next step. Because they feel badly and they want to feel better.”</td>
</tr>
<tr>
<td></td>
<td>“A number of patients also take pain medication. We give the narcotics prescription so patient will keep taking their HIV meds. It's like a marriage”</td>
</tr>
<tr>
<td>Food</td>
<td>“If they don’t have access to healthy food we link them to food banks or Project Angel food that does delivery, or we give them a list of places where they can get meals daily.”</td>
</tr>
<tr>
<td>Assistance with Housing</td>
<td>“If they’re homeless, they’ll give them shelter and link them to a housing specialist, or housing program that will help them with transitional housing or permanent housing.”</td>
</tr>
<tr>
<td>Improvement in Health Condition</td>
<td>“Another incentive is that we help (and we really do help) with housing.”</td>
</tr>
<tr>
<td></td>
<td>“When they see that their viral load starts at 5000 toppings and within three months they’re undetectable . . . that is so exciting for them and for me.”</td>
</tr>
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</table>
DISCUSSION

Three HIV treatment clinics served as the project’s resource centers, one was the primary clinic seeking to improve their client’s HIV treatment adherence rates. Participants included a convenient sample of 12 ethnically diverse care providers (n=12) with a mean age of 43 years. The project's findings identified that personal, social and environmental factors influenced clients’ adherence to treatment. These findings were consistent across all three clinic settings. These findings aligned with research extracted from the literature. It was noted that providers’ attitude and practices contributed to the clients' adherence to treatment. Providers placed greater emphasis on clients' personal factors, such as substance abuse and mental health, as affecting adherence rather than barriers relating to the healthcare system. The healthcare system barriers identified included, lack of cultural diversity among providers; bureaucratic issues relating to insurance coverage, clinic service hours conflicting with clients schedule, fragmented and limited access to specialized services.

A finding worthy of discussion was the observation made related to the influence of the health care system on treatment adherence. Project participants identified clinic operation hours as interfering with adherence. The operating hours were structured and often inconvenient for many of the clients. This did not allow for the accommodation of the lifestyle differences and challenges of the clients served. Treatment clinics were open during hours when most clients would be at work or school and closed those times when clients would most likely be able to attend.

Here we're a very scheduled clinic. In terms of efficiency so there's a lot of people who show up late. There's a lot of no shows. It's hard to address people who don't live on a schedule to, you know? This place is like, if you're 20 minutes late you gotta reschedule. And rescheduling can be pretty far out.
Participants also reported that there was limited staff to adequately service all of the clients' needs. Often times the interventions were based on a response to a crisis.

So I mean I would say because of limitations... I'm mainly responding to crises... We're starting to do more screenings now. But the problem is we don't have a place for people to screen positive. So we've been hesitant to do screenings, because, if people come up highly depressed we don't have the full capacity to provide them with what they need.

Another health care system barrier was the bureaucratic nature and complicated structure of insurance policies. Merely having insurance was not a guarantee of access to care. Due to restrictions regarding coverage, clients who end up needing to move, would not have automatic transfer of their insurance coverage. The client would need to return to the area in which they obtained their insurance in order to receive services or wait an extended period for the transfer process to complete. This may require traveling great distances to obtain their treatment. The process of transferring insurance created barriers to treatment as patients attempted to navigate the paperwork trail. Often clients are left going for several weeks without the needed insurance coverage to obtain their medication.

**Project Limitations**

One limitation of the study is that the information regarding clients' demography was obtained from the treatment provider's perspective and not documented clinic records. The information seemed consistent among providers from the respective clinics. However, the data provided may have been inaccurate in some instances, as it was based on the providers memory and reflection. In retrospect, this information should have been compared with actual clinic data for validation.
Participants were a convenient sample, selected based on who were available and willing to be involved in the project. The participants had to consent to be interviewed and recorded. Self awareness and diplomacy may have influenced some responses. Therefore, there is no guarantee that the participants' responses were totally unbiased.

**Recommendations**

It is well documented regarding how clients' personal and social attitudes and practices influence their adherence to treatment. However, more long term studies should be done from the perspective of health care providers to investigate their role in client's HIV treatment adherence and ascertain what strategies they may utilize to improve treatment adherence. A larger scale study could investigate the extent to which care providers' education level and sexual orientation affected their perceptions of PLWHA. Future projects should investigate long term, how the dynamics of the healthcare system, including hours of operation, affect HIV treatment adherence. The extent to which insurance systems contribute to non-adherence should be explored. This will be of increasing importance since the implementation of the Affordable Care Act.

The Pharmacist and Pharmacy Technician played integral roles in the assessment and treatment of clients in Clinic C. This enhanced pharmacologic treatment adherence through comprehensive medication assessment taken during interactions and meetings with the client. Implementing this method of interaction in Clinic A would be of great benefit in increasing treatment adherence rates. Interpretation of the providers' response alluded to the need for increased funding and implementation of more programs geared towards PLWHA, specifically, those who are homeless, as well as those with mental health and substance abuse issues.
The effectiveness of assessment tools used to identify clients at high risk for treatment non-adherence should be further evaluated. A more in-depth and focused study should be conducted regarding the usefulness of the MCC assessment tool and how it may be redesigned to capture the key information project participants stated was missing from its current format. After examination of this DHS assessment tool, Clinics A& B may find it helpful to redesign their assessment process, as, several of the participants discussed the limitations. The clinics may consider collaborating with Clinic C in developing an assessment tool, which is able to capture the information regarding clients specific needs. Close-ended questions do not allow for elaboration of information. They should include more open-ended questions to allow the client to engage in an in depth discussion regarding their specific needs. A comparison and integration of the two assessment tools may prove beneficial to all clinics.

**Summary**

Several factors emerged as barriers and facilitators to HIV treatment. The ultimate outcome of improving HIV treatment adherence is the reduction of the health and psychosocial implications of the disease globally. The reported information from the providers during interviews revealed that Clinic A, the primary project site, had implemented several best practices comparable to the other sites that facilitated clients' adherence to HIV treatment. The main concern extracted from all three clinic project participants was that regarding the assessment process they were required to use. The general consensus of the participants from clinics utilizing the MCC assessment tool was that the tool was comprehensive but had stipulated criterion that did not allow them to document a true picture of the clients' needs as observed.
The participants who were interviewed for the project were concerned about improving their client’s treatment adherence rates. Based upon the information gathered from the interviews it was calculated that Clinic A had the highest treatment adherence rate with a percentage of 72. The clinics should be applauded, in their effort to seek additional strategies to improve the number of services and resources available for their clients. Interview information revealed that Clinic A implemented an additional MCC team. This allowed them to address the needs of the clients more efficiently and is a possible reason for their improved adherence rate by over 5% within ten months.
REFERENCES


APPENDIX A

FACULTY SUPPORT LETTER

TO: Institutional Review Board for the Protection of Human Subjects

FROM: Faculty Supervisor: Dr. David Kumrow

Department of: Nursing

Telephone Extension: 5X8082

NAME OF STUDENT: Nadine Brown Farr

TITLE OF THESIS OR PROJECT: IMPROVING HIV TREATMENT PROGRAM ADHERENCE IN AN ETHNICALLY DIVERSE URBAN CLINIC

SPONSOR'S STATEMENT: Risk to study participants includes the potential for work interruption due to the length of time and the time of day the interview takes place, and reluctance of the participants to disclose information they perceive to be negative.

The following steps have been taken to protect study participants from these risks: The time of the interview will be set at the convenience of the participants. All information collected will be kept confidential and reported in an aggregate format. No client/patient will be interviewed and no client/patient information will be accessed. Participants will not be required to identify patients' name or provide any other identifying information during the course of the interviews.

This study is important in that it contributes to the scientific knowledge bases in the field of nursing as to how to assess and improve patient's adherence to treatment of Human Immunodeficiency Virus (HIV).

This student's proposed study complies with all Federal regulations and University policy with regard to protection of human subjects from potential harms or risk and with respect to the principles of justice, beneficence, dignity, and respect for persons.

My signature below certifies that I as Faculty Sponsor of this research have read and approve the attached application.

[Signature]

Dr. David Kumrow

Thesis Chair / Research Supervisor Signature and Date
APPENDIX B

IRB APPROVAL

CALIFORNIA STATE UNIVERSITY, LONG BEACH
OFFICE OF RESEARCH & SPONSORED PROGRAMS

DATE: November 9, 2015
TO: Nadine Brown Farr, MPH, MSN
FROM: California State University, Long Beach (IRB)
PROJECT TITLE: [816532-2] IMPROVING HIV TREATMENT PROGRAM ADHERENCE IN AN ETHNICALLY DIVERSE URBAN CLINIC
REFERENCE #: 16-1116
SUBMISSION TYPE: Revision
ACTION: APPROVED
APPROVAL DATE: November 6, 2015
EXPIRATION DATE: November 5, 2016
REVIEW TYPE: Administrative

This is to advise you that the Institutional Review Board for the Protection of Human Subjects (IRB) of California State University, Long Beach, has reviewed your protocol application.

Your application is approved. The requested modifications have been received, reviewed, and accepted.

Approval is for a period of one year and conditional upon your willingness to carry out your continuing responsibilities under University policy. If you would like to continue this research after this one year period, please submit a renewal application and an annual report to the Office of Research & Sponsored Programs two months prior to your expiration date of November 5, 2016.

1. You must clearly indicate in the header or footer of each page of your approved Informed Consent Form the approval and expiration dates of the protocol as follows: "Approved from November 6, 2015 to November 5, 2016 by the CSULB IRB".

2. You are required to inform the Director or Senior Associate Director, Office of Research & Sponsored Programs, in writing (email is acceptable) or through IRBNet within twenty-four hours of any adverse event in the conduct of research involving human subjects. The report shall include the nature of the adverse event, the names of the persons affected, the extent of the injury or breach of security, if any, and any other information material to the situation.

3. You may not change any aspect of your research procedure involving human subjects without written permission from the Director, Office of Research & Sponsored Programs or the Chair of the IRB. Please use the Protocol Modification Form on IRBNet to request any changes.

4. Maintain your research records as detailed in the protocol.
APPENDIX C

DOCTOR OF NURSING PRACTICE PROJECT INTRODUCTION LETTER

Dear:  

My name is Nadine Brown Farr. I am a candidate in the joint California State University Fullerton, Long Beach and Los Angeles Doctor of Nursing Practice program. I am working on a project titled Improving HIV Treatment Program Adherence in an Ethnically Diverse Urban Clinic. My project Chair is Dr. David Kumrow.

I am requesting your written permission to conduct this evaluation project in your clinic. The project seeks to address the challenges of treatment adherence among people living with Human Immunodeficiency Virus (HIV) and the interventions or strategies that assist individuals who are HIV positive. It will involve the evaluation of client’s adherence to treatment through interviews with care providers (Physician/Nurse Practitioner, Nurse, Social Worker, and Case Manager/Case Worker).

I will be conducting recorded semi-structured interviews with the care team to help identify the clients’ reasons for non-adherence to treatment and identify strategies employed to enhance adherence. A further evaluation will be conducted by interviewing staff at two other similar HIV treatment clinics. The gaps and similarities in the programs will be presented to help identify potential solutions to treatment non-adherence.

The interviews will be conducted with staff only and is entirely voluntary. No personal identifying information regarding clients will be required. All information you provide will be kept in the utmost confidentiality. The names of the participants and the name of your clinic will not appear in any project or publications. Participant responses will be reported with no identifying features as to the individual or the clinic. Following data compilation, analysis and interpretation, all data and recordings collected during the process of the project will be destroyed.

Following your permission, I will schedule a time to explain and discuss this project with the health professionals caring for your HIV positive clients. At that time, I will obtain their individual written consent to participate in the project and schedule an appointment at their convenience to conduct the interview.

I have attached a copy of the proposal for your review. If you have further questions please feel to contact me by phone (949) 228-9857 or you may email me at nafbrown2002@yahoo.com.

Please let me know if there is anyone else I need to contact to obtain permission. If you are able to participate in this project, please complete the attached permission letter and return it to me at your earliest convenience.

Thank you for allowing me the opportunity to assist in the process of patient care development while achieving the project objectives.

Sincerely,

______________________________
Nadine Brown Farr, MPH, MSN
Dear Nadine Brown Farr:

Thank you for selecting the ___________________________ Clinic as one of your sites for your Doctoral Project. It is my understanding that our clinic patients will not participate in this project and clinic care coordinator and providers will not be asked to identify patients by name or provide any other identifying patient information during the course of your interviews with them. With this understanding, I hereby grant permission for you to conduct your evaluation project titled “Improving HIV Treatment Program Adherence in an Ethnically Diverse Urban Clinic” here in the ___________________________ Clinic. We look forward to hearing the outcomes of your evaluation in the hopes it will help in identifying potential solutions to poor treatment adherence.

Administrator or Manager Printed Name & Title__________________________________________
Signature: ____________________________ Date: ____________________________
APPENDIX E

PROJECT PARTICIPANT SOLICITATION LETTER

Dear Colleague:

My name is Nadine Brown Farr. I am a candidate in the joint California State University Fullerton, Long Beach and Los Angeles Doctor of Nursing Practice program and I am working on a project titled Improving HIV Treatment Program Adherence in an Ethnically Diverse Urban Clinic. My project Chair is Dr. David Kumrow, Associate Professor of Nursing, CSULB.

The project seeks to address the challenges of treatment adherence among people living with Human Immunodeficiency Virus (HIV) and interventions or strategies employed by Providers to assist individuals who are HIV positive. It will involve the evaluation of client’s adherence to treatment through interviews with some of the care providers with a deep passion to see advancement in the treatment of HIV (Physician/Nurse Practitioner, Nurse, Social Worker, Case Manager/Case Worker). The Manager at your clinic has granted permission for me to conduct this project in your department and I have received IRB approval.

I understand that there are many challenges faced in providing the care for clients affected by HIV and would appreciate if you are able to spend about forty minutes sharing your experiences as well as the innovations that have worked in your clinic with me. Finding time from your busy schedule is also a challenge and it is my plan to travel to San Francisco to meet with you at your convenience.

I will be conducting recorded semi-structured interviews to help identify the clients' reasons for non-adherence to treatment and identify strategies employed to enhance adherence. A further evaluation will be conducted by interviewing staff at two other similar HIV treatment clinics. The gaps and similarities in the programs will be presented to help identify potential solutions to treatment non-adherence.

No personal identifying information regarding clients will be required. All information you provide will be kept in the utmost confidentiality and you have the option not to be recorded. The names of the participants and the name of your clinic will not appear in any project or publications unless agreed upon. Participant responses will be reported with no identifying features as to the individual or the clinic. Following data analysis and compilation, all recordings collected during the process of the project will be destroyed in the specified IRB timeline.

With your permission, I will schedule a time to explain and discuss this project further with you, answer any questions and arrange to obtain your written consent to participate. I have attached a copy of the proposal for your review. If you have further questions please feel free to contact me by phone (949) 228-9857 or you may email me at: nbrownfarr@csu.fullerton.edu.

If you are willing to participate in this project, please contact me at the email provided at your earliest convenience. I appreciate your time and effort. Thank you for giving me the opportunity to assist in the process of patient care development while achieving the project objectives.

Yours Sincerely,

Nadine Brown Farr, MPH, MSN
Doctor of Nursing Practice Candidate, CSULB
APPENDIX F

PROJECT PARTICIPANT CONSENT FORM

Dear Participant:

My name is Nadine Brown Farr. I am a candidate in the joint California State University Fullerton, Long Beach and Los Angeles Doctor of Nursing Practice program. I am working on a project titled Improving HIV Treatment Program Adherence in an Ethnically Diverse Urban Clinic. My project Chair is Dr. David Kumrow, Associate Professor of Nursing, California State University, Long Beach.

The Project: This is a project that seeks to identify the challenges and intervention strategies used in select clinics to address treatment adherence among people living with Human Immunodeficiency Virus (HIV). No client/patient will be interviewed and no client/patient information will be accessed. Participants will be the staff who provide care to the clients/patients in the HIV treatment program.

Treatment care providers will be asked to participate in one semi-structured, individual interview which will take approximately 30 to 40 minutes to complete. The interview will be recorded for transcribing purpose only. The interview will ask participants to describe their basic demographic information, role, length of time working with the HIV treatment program and describe their assessment practices used to identify clients needs in order to promote adherence to their therapy. The interview will also discuss participants' observations of attitudes of clients enrolled in the HIV treatment program who are non-adherent to their treatment regimen.

Risks/Benefits: I anticipate minimal risk, if any, for participants in the study. Your participation will involve the completion of one recorded semi-structured interview. The interview takes approximately 30-40 minutes to complete. The interviewer will ask you to describe your basic demographic information (i.e. role, length of time working with the program) and the assessment practices used to identify clients needs in order to promote adherence to their therapy. In addition, you will be asked to discuss any observations of the attitudes of clients enrolled in your clinic's HIV treatment program that you believe are pertinent to promoting adherence to their treatment regimen. Participants will be asked to identify strategies that help enhance HIV treatment adherence. Participants may be sensitive to disclose information they perceive to be negative, however, all information collected will be kept confidential and reported in an aggregate format. You may feel perceived coercion to participate because your clinic Administrator is aware of the project, however, you will sign the consent privately and arrange for interview at a time and place convenient for you.

The time for the interview may interfere with work hours and a time most convenient for the participants will be arranged.

Participants will complete the interview following their consent to participate and will have the option to refuse to be recorded. Participants will have the option to review only their individual recording and notes if requested. Data collected from the interviews will help determine the challenges as well as strategies that affect HIV treatment adherence.

It is unlikely that participants will be exposed to undue stress or discomfort as a result of their involvement in this project.
Confidentiality: I am only interested in group characteristics; therefore the data will be reported in group format. Results of this project may be published but no names or identifying personal or practice setting information will be included for publication. Project records will be kept confidential to the extent allowed by law. Participants will have the option to review only their individual recording and notes if requested. Data will be kept in a locked file cabinet in the researcher’s home with only the researcher having access to collected data. Following data compilation, analysis and interpretation, all data collected during the process of the project will be destroyed after three years. Notes of recordings will be destroyed immediately following transcription.

Right to Refuse: Your participation is voluntary and you are free to withdraw from participation at any time without suffering penalty or loss of benefits or services you may otherwise be entitled to. You have the right to participate in the interview without it being recorded, if you so wish.

Contact Information: If you have additional questions or would like to know the results of the project, please contact Nadine Brown Farr at (949) 228-9857 or email: nbrownfarr@csu.fullerton.edu or nafbrown2002@yahoo.com. You may also contact the Institution Review Board at California State University, Long Beach at 562-985-2502.

Conflict of Interest: The researcher, Nadine Brown Farr, does not have financial (or otherwise) conflict of interest relating to the results of this study.

Consent Clause: I have carefully read and/or I have had the terms used in this consent form and their significance explained to me. By signing below, I agree that I am at least 18 years of age and agree to participate in this evaluation project. I will indicate by initialing either yes or no below whether I consent to have my interview recorded. If you do not wish to participate, the consent form should be left blank.

How to submit consent: Place the consent form in the attached envelope regardless of whether or not you wish to participate in the project. Please seal the envelope and place it in the locked ballot box at the designated location identified during the question and answer session.

I consent to have my interview recorded. Yes____________ No____________

_______________________       __________________       __________
Participant’s Printed Name               Signature              Date

_______________________       __________________       __________
Witness Printed Name                   Signature              Date

Page 2 of 2
APPENDIX G

PROJECT DEMOGRAPHY QUESTIONS

Demographics

1. How old are you? _______ years.

2. What is your sex or gender?
   _____ Female
   _____ Male
   _____ Female to Male Transgender
   _____ Male to Female Transgender
   _____ Other, please describe: ____________
   _____ Decline to state

3. How would you describe your race/ethnicity?
   _____ Asian/Pacific Islander
   _____ African American/Caribbean American/Black
   _____ Hispanic/Latino
   _____ Native American/American Indian
   _____ White/Caucasian (non-Hispanic)
   _____ Other, please describe: ____________
   _____ Decline to state

4. What is the highest level of education that you have completed? (check only one)
   _____ High School or GED
   _____ 2 years of College/Associates Degree/Technical School
   _____ College or University (B.A. or B.S.)
   _____ Graduate Degree (Master’s, PhD, Professional Degree)
   _____ Decline to state

5. What is your sexual orientation?
   _____ Gay/Lesbian/Homosexual
   _____ Straight/Heterosexual
   _____ Bisexual
   _____ Other, please describe: ____________
   _____ Decline to state
The questions below refer to the demography of the clients you serve. You may give your answer in approximate percent or numbers. In thinking about the demographic make-up of the patients you serve, approximately what percentage is of the gender, age and ethnicity listed below:

6. What is the sex or gender of the clients you serve?
   _____ Female
   _____ Male
   _____ Female to Male Transgender
   _____ Male to Female Transgender
   _____ Other, please describe: ____________
   _____ Unable to state

7. What is the age distribution of the clients you serve?
   a. Under 18yrs_________
   b. 18-24yrs___________
   c. 25-30yrs___________
   d. 31-35yrs___________
   e. 36-40yrs___________
   f. 41-45yrs___________
   g. 46-50yrs___________
   h. 51-55yrs___________
   i. 56-60yrs___________
   j. 61-65yrs___________
   k. 66-75yrs___________
   l. 76-85yrs___________
   m. 85yrs +_____________

8. What is the race/ethnicity of the patients you serve?
   _____ Asian/Pacific Islander
   _____ African American/Caribbean American/Black
   _____ Hispanic/Latino
   _____ Native American/American Indian
   _____ White/Caucasian (non-Hispanic)
   _____ Other, please describe: ____________
   _____ Unable to state

9. What is the approximated employment status of the clients you serve?
   _____ Full-time
   _____ Part-time
   _____ Looking for Job
   _____ Not looking for Job
   _____ Unemployed
   _____ Student
   _____ Other ___________________________
APPENDIX H

PROJECT INTERVIEW QUESTIONS

IMPROVING HIV TREATMENT PROGRAM ADHERENCE IN AN ETHNICALLY DIVERSE URBAN CLINIC

INTERVIEW QUESTIONS

Introduction: Thank you for taking the time to participate in this interview. I will be asking you some questions to identify the challenges and intervention strategies you use to address treatment adherence among the Human Immunodeficiency Virus (HIV) positive clients you have identified as high risk. For the purpose of this interview, clients will only refer to individuals who are HIV positive and enrolled in a treatment program at your clinic. Please be reminded that this interview will be recorded based on your indication in consent. To ensure anonymity, your interview will be assigned a code number for transcribing purposes. I will not be recording your name or any other personal identifying information. You are asked not to refer to clients by name or provide any other personal identifiers. Do you have any questions before we begin?

1. What is your job title?

2. Please explain to me what you do on a daily basis here at the clinic?

3. On average, about how many HIV positive clients are registered in this clinic's treatment program who have been identified as high risk? 

4. Generally how many clients do you serve on a daily basis?

5. Approximately what percentage of your clients would you say are non-adherent to their treatment regimen?

6. What difficulties or challenges do you personally face in relating to your clients who are non-adherent to treatment?

7. Do any of these words describe your feeling towards any of your clients who are non adherent to their treatment? Select all that apply from the list provided.
Patient, understanding, tolerant, lenient, frustrated, angry, disappointed, helpless, hopeless. Please list any other words that come to mind.

8. How do you assess the physical and psychosocial needs of clients enrolled in this treatment program?
   a. Do you use an assessment protocol?
   b. Please explain the assessment process.

9. How helpful is this assessment protocol in its ability to capture the facilitators and barriers to treatment adherence?

10. What do you think is missing, if anything, in this assessment protocol as to its ability to provide a comprehensive or holistic picture of your client’s needs?

11. What do you believe are some of the causes that impact your clients' ability to be adherent to their treatment?

Resources:

12. Tell me how your high risk clients access available resource to meet their basic daily needs.

13. What strategies seem to help your clients in taking advantage and using the available resources your clinic offers them? (What do you do?)

14. What are your perceptions as to why clients are reluctant to access these resources?

15. Tell me how clinic funding, or lack of funding, affects client non-adherence?
   a. What aspect of clinic funding or policy directs your care, in either a positive or negative way?
b. If funding impacts adherence: What are some of the areas that may need additional funding to help clients become more adherent in their treatment program?

16. What do you believe are the top two to three incentives provided to your clients that seem to work the best to help them adhere to their treatment?

The following questions are related to services and support to the client in the community:

17. How are priorities set for your clients in relation to their treatment plan?

18. What, in your experience, has been the best and least effective approach in facilitating adherence for your high risk clients?

19. How do you think your clients view clinic staff's dedication in helping them adhere to their treatment plan?

20. What do you or your clinic do to make clients feel that there is a welcoming atmosphere for them in relation to issues of age, gender, sexual orientation (including transgender clients), race or ethnicity? Explain your answer.

   a. Do you believe this is a factor in adherence?

21. In light of everything we have spoken about, is there anything else you think is important to mention?

22. What questions do you have for me?

Thank you for taking the time to complete this interview. Feel free to contact me or Dr. Kumrow should you have any other questions.

Prompts for interviewer:
- Tell me more about that?
- Can you give me an example of that?
APPENDIX I

LIST OF RESEARCH PANEL

Preview Questionnaire:

Armendariz, Gina, EdD
Graduate Learning Specialist
California State University, Fullerton

Nation, Austin, RN, PHN, MSN, PhD(c)
Nursing Doctoral Candidate
University of California, San Francisco
School of Nursing - Community Health Systems

Zepf, Roland, MS, RN, ACRN, PhD(c)
Nursing Doctoral Student
University of California, San Francisco
School of Nursing - Department of Community Health Systems

Data Analysis:

Armendariz, Gina, EdD
Graduate Learning Specialist
California State University, Fullerton

Gonzalez, Maria, DPA, MSN, RN, NE-BC
Retired VA Healthcare System
Assistant Professor, West Coast University

Martinez, Randall, PhD
Professor of Psychology
Department of Psychiatry, Cypress College
APPENDIX J

LINKS TO ASSESSMENT FORM AND DOCUMENTS FROM DEPARTMENT OF PUBLIC HEALTH

County of Los Angeles Public Health Department Division of HIV and STD Programs
http://publichealth.lacounty.gov/dhsp/MCC.htm

Casewatch Handbook for HIV/AIDS Linkage Case Management Automated Case Management Systems, Inc. and the Division of HIV and STD Programs

Medical Care Coordination (MCC) Assessment Guidance

Medical Care Coordination (MCC) Assessment Form
## APPENDIX K

### PARTICIPANTS PERCEPTION OF TOP INCENTIVES FACILITATING TREATMENT ADHERENCE

<table>
<thead>
<tr>
<th>Incentives</th>
<th>Notable Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Love, Compassion &amp; Staff Support</td>
<td>&quot;Make them feel loved and that we care about them genuinely and when (....... does the intakes and meets the patients, he’s the one that meets them for the first time and he’ll introduce us to our future patient in case management so that they have a face to remember or that handshake, that hello..&quot;</td>
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<td></td>
<td>&quot;I think that is a big incentive to being in the clinic, to have people that actually care about your well being, and want you to be healthy, and want you to benefit from all this research.&quot;</td>
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<td>&quot;Knowing that the support is there, they can call their doctors, I think that’s a big incentive.&quot;</td>
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<td></td>
<td>&quot;Know that their providers will be the first person to contact; if their provider is not returning a call, they can call me and I can always relate the message to the doctor?&quot;</td>
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<td></td>
<td>&quot;Our clinic is very family oriented so we try to treat every individual with respect and dignity.&quot;</td>
</tr>
<tr>
<td></td>
<td>.. we are always available to answer any questions.”</td>
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<td></td>
<td>&quot;So our patients are able to call and talk to our providers throughout the week. We do have ongoing follow up and our patients are called the day before their appointments to make sure they’re always in contact. So I’m not sure if that’s an incentive, but it’s definitely help.”</td>
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<td></td>
<td>&quot;The benefits counselors are key because I used to do all that. You know the patients don't have insurance, they just, if there's a lapse or something happens then forget it. They can't even get in the door. So I think that is really important.”</td>
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<td></td>
<td>&quot;Our social work staff...that is a huge incentive.”</td>
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<td></td>
<td>&quot;Education 'and' the compassionate staff that’s working with you.”</td>
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<tr>
<td></td>
<td>&quot;Education and emotional support. Yeah, that works the best for them.”</td>
</tr>
<tr>
<td>Transportation</td>
<td>&quot;Their temp card, which is their bus transportation card. Those we provide to clients who have a disability. So the patient has to be disabled to get rides to and from medical appointments.”</td>
</tr>
<tr>
<td></td>
<td>&quot;So getting back and forth is a huge incentive, transportation is a huge incentive.”</td>
</tr>
<tr>
<td></td>
<td>&quot;We give them tokens that they can get here by bus. Getting a disabled cap card, we link them so if they qualify for Access, we make sure they have the Access obligation so they can get it. We have binders and binders full of resources.”</td>
</tr>
<tr>
<td></td>
<td>&quot;On the positive side, we have a grant that we've been getting for a few years that is bus tokens and taxi vouchers, so we can get through some of the transportation barriers.”</td>
</tr>
<tr>
<td></td>
<td>&quot;We offer bus tokens, you know, transportation vouchers. And that helps a lot.”</td>
</tr>
</tbody>
</table>
| Support Groups & Self Motivation | "If transportation is an issue then we’ll provide them with a bus pass or tokens.

I’m gonna say our Christmas and Thanksgiving get together. I would also say because they get to work with awesome people.”

"These are self-satisfying things. We try to engage clients to getting in to see that this is for your benefit and so therefore the incentive has to be..self-cultivated.”

"There’s no reward besides the positive praise and just giving them the confidence to continue taking it over a long period of time.”

"High risk group, since it's hard to get them to make appointments we try to get them to come every Thursday for breakfast and then we try to schedule all their appointments on Thursday.”

"Yeah, the breakfast club helps.”

"On the other hand, we know from our experience (although the literature has shown mixed results) that patients are really motivated by vouchers, gift cards, things like that.”

One of the great things I think our providers do is help patients understand that this is how you're feeling today, but if you take the meds, if you're adhering with the meds and you do what we've outlined, this is how you will feel. This is what you can expect or should expect. When patients hear that you won't believe it, I think they're incentivized to take the next step. Because they feel badly and they want to feel better.”

"A number of patients also take pain medication. We give the narcotics prescription so patient will keep taking their HIV meds. It's like a marriage. And you know our grant with the city is what funds our pharmacy services, our nutrition services, and our case management services.

"I mean for patients who are on controlled drugs like Benzodiazepines and opiates, they won't get refills unless they come in...that will include getting labs done as well.”

"I believe when patients see the food bank. That’s a big part of our program – they have to meet with the RN who completes the application for them to go to the food bank.”

"If they don’t have access to healthy food we link them to food banks or Project Angel food that does delivery, or we give them a list of places where they can get meals daily.”

"To keep them engaged they have to complete a certification every six months. So for patients who are receiving their dental care for free they have to be eligible at all times so they have to be compliant with that to receive their HIV dental care.”

If they’re homeless, they’ll give them shelter and link them to a housing specialist, or housing program that will help them with transitional housing or permanent housing.”

"Another incentive is that we help (and we really do help) with housing.”

"When they see that their viral load starts at 5000 toppings and within three months they’re undetectable..that is so exciting for them and for me.”

"One is healthy outcomes.”

Pharmacy Support | "One of the great things I think our providers do is help patients understand that this is how you're feeling today, but if you take the meds, if you're adhering with the meds and you do what we've outlined, this is how you will feel. This is what you can expect or should expect. When patients hear that you won't believe it, I think they're incentivized to take the next step. Because they feel badly and they want to feel better.”

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Assistance with Housing | "One of the great things I think our providers do is help patients understand that this is how you're feeling today, but if you take the meds, if you're adhering with the meds and you do what we've outlined, this is how you will feel. This is what you can expect or should expect. When patients hear that you won't believe it, I think they're incentivized to take the next step. Because they feel badly and they want to feel better.”

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Seeing Improvement in Health Condition |

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