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# Exploring Financial Incentives To Promote Adherence To Anti-Retroviral Medications In People Living With Hiv/aids

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# Exploring Financial Incentives To Promote Adherence To Anti-Retroviral Medications In People Living With Hiv/aids

## **Abstract**

With the introduction of Highly Active Anti-Retro Viral Therapy (HAART), Human Immunodeficiency Virus (HIV) infection has become a manageable chronic condition (Deeks, Lewin & Havlir, 2013). Research suggests that if all HIV positive individuals could be identified and immediately started on HAART and if, they maintained good adherence to the medication, the HIV/AIDS epidemic could be effectively controlled and eventually eliminated (Granich, Gilks, Dye, De Cock & Williams, 2009). However, adherence to HAART remains a challenge for those living with HIV and their health care providers (Nachega et al., 2012; Mills et al., 2006). Efforts are underway to improve adherence to HAART among people living with HIV/AIDS (Chaiyachati, Ogbuoji, Price, Suthar, Negussie & Barnighausen, 2014). Financial incentives have been shown to be effective in improving adherence to HAART (Giles, Robalino, McColl, Sniehotta & Adams, 2014). However, the way financial incentives work to promote adherence behaviors in a clinical setting needs to be better understood before large-scale interventions are developed using this tool. The present study employed a Constructivist Grounded Theory approach (Charmaz, 2006) to qualitatively answer the question: How does the provision of financial incentives affect the process of adherence to anti-retroviral medication in individuals with HIV infection? The study was conducted at Housing Works, which is a community based HIV service organization in New York City. The participants were recruited from an adherence promotion intervention implemented by Housing Works, The Viral Load Suppression (VLS) program, which used financial incentives along with other services to promote adherence. Results indicate that there were symbolic and material aspects to the effects of financial incentives on motivation to adhere to medication. The context specific facilitators of and barriers to adherence were both influenced by financial incentives and the facilitating factors, in turn, influenced the effect of the incentives. The implications of the results are discussed specifically with regards to theory development, practice directives, policy recommendations and future directions for research in financial incentives to promote adherence to HAART.

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**EXPLORING FINANCIAL INCENTIVES TO PROMOTE ADHERENCE TO ANTI-RETROVIRAL  
MEDICATIONS IN PEOPLE LIVING WITH HIV/AIDS**

Sambuddha Chaudhuri

A DISSERTATION

in

Social Welfare

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in

Partial fulfillment of the Requirements for the

Degree of Doctor of Philosophy

2017

**Supervisor of Dissertation**

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**Graduate Group Chairperson**

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Dr. Ezekiel Dixon-Román, Associate Professor, School of Social Policy and Practice

*Dedicated to the patients, advocates, doctors, nurses, social workers, policy makers, researchers and many others who continue to fight for securing health and well-being for one and all.*

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and India. She has listened patiently when I whined about my troubles or joined me enthusiastically in celebrating the small successes along the way. She has advocated on my behalf with the school authorities to make it possible for me to spend large chunks of time home, in India, during times of personal and family crisis. She has accommodated my physical absences from the campus and yet facilitated my work in her projects. She has worked with me to find summer grants and encouraged my participation in conferences and workshops. I was greatly reassured that she was just a phone call away anytime of the day and night, if I needed her. Thank you so much Andrea. I hope we will keep this academic and personal friendship for all times to come.

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**ABSTRACT****EXPLORING FINANCIAL INCENTIVES TO PROMOTE  
ADHERENCE TO ANTI-RETROVIRAL MEDICATIONS IN  
PEOPLE LIVING WITH HIV/AIDS****Sambuddha Chaudhuri****Dr. Andrea Doyle**

With the introduction of Highly Active Anti-Retro Viral Therapy (HAART), Human Immunodeficiency Virus (HIV) infection has become a manageable chronic condition (Deeks, Lewin & Havlir, 2013). Research suggests that if all HIV positive individuals could be identified and immediately started on HAART and if, they maintained good adherence to the medication, the HIV/AIDS epidemic could be effectively controlled and eventually eliminated (Granich, Gilks, Dye, De Cock & Williams, 2009). However, adherence to HAART remains a challenge for those living with HIV and their health care providers (Nachega et al., 2012; Mills et al., 2006). Efforts are underway to improve adherence to HAART among people living with HIV/AIDS (Chaiyachati, Ogbuoji, Price, Suthar, Negussie & Barnighausen, 2014). Financial incentives have been shown to be effective in improving adherence to HAART (Giles, Robalino, McColl, Sniehotta & Adams, 2014). However, the way financial incentives work to promote adherence behaviors in a clinical setting needs to be better understood before large-scale interventions are developed using this tool. The present study employed a

Constructivist Grounded Theory approach (Charmaz, 2006) to qualitatively answer the question: *How does the provision of financial incentives affect the process of adherence to anti-retroviral medication in individuals with HIV infection?* The study was conducted at Housing Works, which is a community based HIV service organization in New York City. The participants were recruited from an adherence promotion intervention implemented by Housing Works, The Viral Load Suppression (VLS) program, which used financial incentives along with other services to promote adherence. Results indicate that there were symbolic and material aspects to the effects of financial incentives on motivation to adhere to medication. The context specific facilitators of and barriers to adherence were both influenced by financial incentives and the facilitating factors, in turn, influenced the effect of the incentives. The implications of the results are discussed specifically with regards to theory development, practice directives, policy recommendations and future directions for research in financial incentives to promote adherence to HAART.

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## **Chapter 1: The HIV Epidemic, Adherence to HAART and Financial Incentives**

### **Introduction**

Research has suggested that the HIV/AIDS epidemic can be effectively controlled (reduction in mortality & morbidity and effectively end ongoing transmission) if all individuals with HIV can be identified and they are started on and adhere to anti-retroviral medication (Granich, Gilks, Dye, De Cock, & Williams, 2009). Over the last two decades, scholars have repeatedly found evidence that an early start to Anti-Retroviral Therapy (ART) for HIV-positive persons leads to preservation of immune function thereby maintaining health and well-being of the infected persons along with significantly reduced risk of ongoing HIV transmissions (Günthard et al., 2016; Marrazzo et al., 2014; Opravil et al., 2002; Hogg et al., 1998; Pallela et al., 1998). These findings point to an exciting future for HIV prevention and treatment.

The long-term success of effective Highly Active Anti-Retroviral Therapy (HAART) is, however, limited by the necessity of high levels of adherence to treatment schedules. When patients adhere to less than 90% of the recommended doses, a steep decline in the treatment response is observed (Gross, Bilker, Friedman & Strom, 2001; Sethi et al., 2003). Although newer, more potent regimens allow for lower levels of adherence (Kobin & Sheth, 2011), yet non-adherence is highly correlated with mortality in people living with HIV/AIDS (PLWHA) (Gordon, Gharibian, Chong & Chun, 2015; Kahana, Rohan, Allison, Frazier & Drotar, 2013; Mugavero et al., 2009; Wood et al., 2003). Several efforts are underway, to improve the adherence to anti-retroviral therapy,

so PLWHA experience good quality of life, while at the same time ,the HIV epidemic is effectively controlled. Financial incentive programs, peer group-based support interventions and directly observed therapy are a few of the promising approaches to tackle the problem of poor adherence among PLWHA (Kanters et al., 2017; Linnemayr & Rice, 2016; Sabin et al.,2015; Mannheimer, & Hirsch-Moverman, 2015; Chaiyachati, Ogbuoji, Price, Suthar, Negussie & Barnighausen, 2014).

This chapter will provide a brief overview of the history of HIV care in the USA and the ways it has changed the manner in which Public Health and Medical Research has responded to the crisis of epidemics. This will be followed by an account of how adherence to the anti-retroviral medical regimes fits into this history of responses to HIV epidemic and the challenges to adherence. The final section of this chapter will explore the ways in which financial incentives can play a role in promoting adherence in the fight against the HIV epidemic. The chapter will conclude by introducing the question under study: how can we better understand the role of financial incentives in the context of adherence and HIV clinical care?

### **History of HIV care in the USA**

HIV history and activism have changed many of the ways public policy and public health are practiced today. The early 1980s in the US witnessed the emergence of a hitherto unknown syndrome that, at first, seemed to claim the lives of previously healthy, mostly young homosexual men (Smith & Whiteside, 2010). In this climate of confusion over a new disease, the rising number of deaths coupled with homophobia

and the conservative turn in the national politics led to a moral panic about the “sinful” lifestyle choices of gay men (De Wall, 2006). This new disease, or syndrome was dubbed gay related immunodeficiency disease (GIRDS), suggestive of a causal link between homosexual lifestyle and the degenerative disease (Fee & Krieger, 1993; Patton, 2002). Gay men faced overt discrimination when they wanted to access health services (Smith & Whiteside, 2010). However, in 1983 when the causal HIV virus was discovered along with increased reporting of cases among women, children, and transfusion recipients, it became apparent that this disease could affect anyone if they had been exposed to the virus.

The gay community had recently consolidated some political and social leverage in the immediate post-civil rights, sexual liberation decades of the 1960s and 70s. Faced with this new scourge, various gay civil rights groups responded by organizing against the resurgent stigma and discrimination in the wake of HIV/AIDS epidemic. Recognizing the greater vulnerability of gay men towards the disease, activist groups rejected the public health logic of quarantine and isolation of those infected (Rosenbrock et al, 2000). It was argued that such moves would further marginalize individuals and drive the epidemic underground. Instead, groups started advocating for better health care and access to services for the afflicted. By mid 1980s it became clear that HIV spread was associated with basic life giving and pleasurable acts of sexual intimacy and that no one was, technically, immune from this yet intractable disease. Furthermore, activist groups began to advocate for a social justice approach to HIV which emphasized the social determinants of health and framed the risk of infection and

resultant stigma as one that endangered the civil liberties of the affected citizens (Fee & Krieger, 1993; Mann & Tarantola, 1998). The force of these claims, together with the panic of a generalized epidemic, led to the belief that an exceptional disease such as AIDS needed exceptional response, resulting in what has been described as “AIDS exceptionalism” (Bayer, 1994). By the late 1980s, the AIDS movement had given birth to the ACT UP coalition, that embodied the spirit of public health advocacy and AIDS exceptionalism. It called for policies that ensured quick translation of bench research on disease modifying drugs into easily available medication for HIV infected individuals (Patton, 2002).

In the 1996, at the International AIDS conference in Vancouver, Canada, Highly Active Anti-Retroviral Therapy (HAART) was launched. Since then HIV/AIDS have been transformed from a fatal disease for which there was only symptomatic treatment, to a condition that can be successfully managed with long term medication regimes (Deeks, Lewin & Havlir, 2013; Smith & Whiteside, 2010). HAART has revolutionized the clinical outcomes of HIV infection and the massive public health response of the 1980s and 1990s was mostly effective in averting the feared pandemic with new infections falling from about 130,000 in 1984 to approximately 60,000 in 1991 to about 47,500 in 2010 (El-Sadre, Mayer & Hodder, 2010; CDC, 2012). The incidence rates of HIV had remained at about 50,000 infections per year since the mid-1990s in the United States (CDC, 2012) with a slight decrease to in 2015 with a reported 39,513 new cases (CDC, 2017).

It was expected that HAART, with its suppressive effects on viral replication, would result in lower rates of new infection, but this goal has not yet been realized (El-Sadre, Mayer & Hodder, 2010). Moreover, certain “high risk groups”, such as African Americans, Latinos and gay and bisexual men of all races/ethnicities, continue to be disproportionately affected by the disease. Cohen (1999) in her book “The Boundaries of Blackness: AIDS and the breakdown of black politics” has documented how the epidemic has been particularly devastating for African American communities in the major US cities. The most vulnerable groups within the African American communities such as gay men, injection drug users and low-income women have borne the brunt of the disease (Cohen,1999). They had to fight the multiple marginalization stemming from their positions of race, class, gender, and sexuality to secure services and promote awareness about the epidemic. As the latest statistics prove, communities of color continue to withstand the worst of the disease (CDC, 2012) and are in need for services that meet their medical, social, and economic needs if this trend is to be reversed.

Thus, in the present decade, although much of the impetus behind the original AIDS exceptionalism has dissipated, the social justice approach to dealing with the epidemic is not yet redundant. There remain huge gaps with regards to implementing better access and adherence to the improved medicines, with the aim of improving quality of lives of PLWHA, reducing new infection rates and ultimately ending the AIDS epidemic.

## **Importance of adherence to HAART**

**HIV in the era of HAART.** Ever since the introduction of anti-retro viral therapy in the early 1990s, the clinical history of HIV infection and AIDS has changed dramatically. A significant decline in the incidence of opportunistic illness and death in HIV positive patients was associated with combination antiretroviral therapy (ART) from 1994 through 1998 (Moore & Chaisson,1999). Around 1997, highly active antiretroviral therapy (HAART), an improvement on the extant anti-retroviral medication, was introduced. A study with the HIV infected beneficiaries of the United States Department of Defense showed that with improvement in HIV treatment, proportionally fewer patients were dying of the HIV-related illnesses (Crum et al., 2006). In the post-HAART era (since 1997), cardiac disease, trauma, and liver disease, as opposed to opportunistic infections seen in the earlier decade, emerged as important causes of death in these patients on anti-retroviral therapy (Crum et al., 2006). Similar results were reported in other countries where improved anti-retroviral therapy was made available for HIV infected patients (Wong, Chan & Lee, 2004).

HAART produces rapid improvement in the biomarkers used to determine the prognosis of HIV infection and progression of AIDS: CD4 cell count and circulating Viral RNA copies (Nixon & Landay,2010; Wood et al.,2006). Greater proportions of patients on HAART, had CD4 counts greater than 200 cells/mL at the time of their death as compared to those in the pre-HAART era, indicating that more patients were dying with relative immune preservation (Crum et al.,2006). Undetectable levels of

viral RNA are frequently reported in patients who have been successfully initiated and maintained on HAART (Nachega et al., 2007).

A high CD4 cell count means less chances of opportunistic infections and progression to AIDS (Nixon & Landay, 2010). Patients on HAART report better quality of life and lower frequencies of infection (Rubaihayo, Tumwesigye, Konde-Lule & Makumbi, 2016; Nakagawa et al., 2012; Spire et al., 2002). Low volumes of circulating viral RNA results in effective suppression of transmission of the virus from HIV positive patients to uninfected sexual partners (Rodger, Bruun, Cambiano, Vernazza, Strada, & Van Lunzen, 2014; Crum et al., 2006). Given the biomedical efficacy of HAART, clinical recommendation now strongly supports early initiation of HAART with all HIV positive patients (Günthard et al., 2016; Marrazzo et al., 2014).

**Adherence and HAART.** The spectacular benefits of HAART, described above, is limited by its rigorous drug regime. Most regimes in earlier years after introduction of HAART therapy asked patients to take multiple doses at different times of the day, every day, although more recent regimes allow simpler (e.g. once a day) dosing schedules (Nachega et al., 2014; Kobin, & Sheth, 2011). Adherence is a significant determinant of viral suppression in individuals who are newly initiated to an antiretroviral regimen (Li, Gallien, Ribaudou, Heisey, Bangsberg & Kuritzkes, 2014). After the first month of therapy a reduction in adherence is often noted (Gross et al., 2001). Substantial CD4 T cells gains are possible among highly adherent patients (Gross et al., 2006; Wood et al., 2006). Moreover, the benefits of HAART therapy decline when adherence levels fall below 90% (Bangsberg, 2006), though lower levels

of adherence (around 80%) have been shown to produce sustained viral suppression in many patients (Kobin, & Sheth, 2011). Incomplete adherence to HAART over time has been found to be strongly associated with increased mortality (Gordon, Gharibian, Chong & Chun, 2015; Kahana, Rohan, Allison, Frazier & Drotar, 2013; Lima et al., 2001). Thus, there is an urgent need to explore and implement interventions that promote adherence and help reap the benefits of HAART both at the level of the individual and that of the population (Kanters et al., 2017; Günthard et al., 2016).

**Barriers to Adherence.** Scholars have recognized several important barriers that affect adherence to HAART. Adherence to medication regimes in chronic illnesses, such as hypertension and diabetes, are influenced by factors like adverse effects, regimen complexity, perception of disease severity and psychosocial factors of substance use and depression (Grenard et al., 2011; Phatak & Thomas III, 2006; Osterberg & Blaschke, 2005; Kim, Han, Hill, Rose & Roary, 2003). However, the requirement for higher levels of adherence to HAART in HIV positive patients, sets it apart from other chronic diseases and results in additional stress and higher treatment failure rates in PLWHA (Bangsberg et al., 2000; Boden et al., 1999).

***Regimen related factors. Regimen complexity.*** HAART regimens are characterized by multiple daily doses and may involve food restrictions and complex dose scheduling (Mills et al., 2006; Chesney, Morin & Sherr, 2000). A complex regimen and high pill burden can impede adherence (Saber, Neilands, Vittinghoff, Johnson, Chesney & Cohn, 2015; Altice et al., 2001; Bartlett et al., 2000). However, some scholars have pointed out that patient's perception of how well the regimen fitted



in with their daily routine better predicted adherence rather than absolute pills counts and apparently complicated regimes (Shubber et al., 2015; Gifford et al., 2000). More recent pharmacological advancements have enabled once, twice, or thrice daily dosing which greatly promises to improve adherence patterns (Kobin&Sheth,2011; Nagecha et al., 2014; Rosenbach, Allison & Nadler, 2002).

*Adverse effects:* One of the most frequent reasons for non-adherence to HAART is adverse side effects (Al-Dakkak, Patel, McCann, Gadkari, Prajapati & Maiese, 2013; Nacheha et al., 2014; Saberi, Neilands, Vittinghoff, Johnson, Chesney & Cohn, 2015;). They can be either transient like diarrhea and nausea or long-term ones of lipodystrophy, dyslipidemia, and neuropathy (Chesney, 2003). Side effects may be actual or perceived, but whenever reported, it is advisable to either quickly discontinue or modify the current regimen (Morcroft et al., 2001). HAART regimens are changed more often due to side effects rather than treatment failures (Catz et al.,2000; Monforte et al.,2000; Morcroft et al., 2001;).

The most common side effects that cause considerable distress among patients include fatigue, diarrhea, and stomach pain. These can usually be successfully treated and adherence can be maintained without major changes of regimen. However, lipodystrophy (usually manifested as fat accumulation in different parts of the body like upper back, neck, and abdomen, with peripheral fat wasting in face legs arms and buttocks (Carr et al.,1998; Gervasoni et al.,1999)) may be more difficult to treat (Kasper, Arboleda & Halpern, 2000), prompting many patients to discontinue or poorly adhere to HAART. Actively monitoring of lipid levels and insulin status together with

other metabolic markers can help predict and prevent the onset of lipodystrophy (Chesney, 2003). Newer agents that are not reported to cause dyslipidemia may be used as first line of treatment to reduce chances of intractable side effects like lipodystrophy (Haas et al., 2002).

***Patient related factors.*** Individuals who experience symptoms of HIV/AIDS are often more likely to be adherent despite high pill burden and complex schedules (Mills et al., 2006; Gao, Nau, Rosenbluth, Scott & Woodward, 2000) although newer drugs have simpler once daily schedules. Forgetting to take the pill is the most frequently cited reason for non-adherence and individuals who regain well-being and resume their usual routine often forget more frequently than their symptomatic counterparts (Langebeek et al., 2014; Mills et al., 2006; Chesney et al., 2000). Lack of understanding of the prescribed regimen along with confusion about sequence of food, water and drugs can lead to confusion and low levels of adherence (Catz et al, 2000; Chesney et al., 2000).

***Substance use:*** Although habitual substance has been correlated with non-adherence (Shubber et al., 2016, Mills et al., 2006; Chesney et al, 2000a; Ostrop, Hallett & Gill, 2000), good adherence may be achieved if provider adequately works with the patient around concerns of safety, regimen complexity and side effects (Chesney, 2003). Intravenous drug users may be hesitant to start HAART therapy but once started, their adherence patterns resemble other groups (Mocroft et al. 1999).

*Depression and stress:* Depressed individuals are less likely to feel motivated for self-care and are prone to poor adherence (Shubber et al.,2016; Saberi, Neilands, Vittinghoff, Johnson, Chesney & Cohn, 2015; Paterson et al., 2000; Murphy et al., 2001). Social support (Langebeek et al., 2014; Shubber et al.,2015; Paterson et al., 2000) and social stability can greatly improve adherence outcomes in all individuals especially those that experience stress and depression.

*Socioeconomic issues:* Individuals living in poor socioeconomic conditions are more likely to be non-adherent (Shubber et al., 2015; Mills et al., 2006; Spire et al.,2002; Chesney et al., 2000b). However, it has been argued that homeless individuals and those living on welfare in poor socioeconomic circumstances may be assumed to be less likely to be adherent and hence not promptly offered HAART on being diagnosed HIV positive. If providers can attempt to work with patients on issues of pill burden, complex regimes, side effects along with challenges of poor living conditions, better adherence results may be obtained.

*Patient belief systems:* Individuals who are non-adherent are more likely to misunderstand the relationship between not taking their HAART medication, their viral and CD4 T Cell counts and disease progression (Chesney et al., 2000a;). Confidence in the efficacy of HAART in controlling the disease is associated with greater adherence (Mills et al., 2006). HAART is believed to interfere with the street drug high and conversely streets drugs are assumed to reduce HAART efficacy, leading to poor adherence in some substance users (Ng, Rosen, Malcom, Stein & Stone, 2000).

*Patient-provider relationship:* Many of the above-mentioned adherence barriers can be effectively dealt with by supportive care providers (Ickovics & Meade, 2002). Patients' belief in their physician's efficacy is shown to influence adherence to their prescriptions (Mills et al., 2006; Siegel, Karus & Schrimshaw, 2000). Adherence can be improved if providers and patients work through the issues of regimen inconvenience, side effects, clarity and quality of communication and patient involvement in care decisions (Mills et al., 2006; Chesney, 2000a).

**Adherence as a dynamic behavior.** Chronic diseases which require long term adherence usually elicit complex responses from the patients. Adherence in this context is better understood as a dynamic behavior where each of the above factors or group of factors potentially influence each other altering the adherence in indirect and / or reciprocal ways (Ickovics & Meade, 2002). For example, complex dosing schedules may lead to stress and the resultant failure to adhere may depress the patient which can lead to negative belief and greater non-adherence. Disadvantaged socioeconomic situation may limit one's access to competent health care providers, leading to mistrust in the available physicians and other resources resulting in poor patient-provider relationship and low levels of adherence. Conversely, better adherence may lead to better health outcomes which can positively influence faith in the regimen and the provider which may further improve adherence. Hence, adherence behavior can be conceptualized as a matrix of interrelated factors that shift over time and affect each other and the outcome in multiple and complex ways (Mills et al., 2006; Carrieri et al., 2001; Spire et al.,

2002). Interventions that seek to improve adherence must try to simultaneously affect multiple locations in this matrix (Langebeek et al., 2014; Ickovics & Meade, 2002).

### **Financial incentives to improve adherence**

Financial incentives that promote desirable behavior form a part of economic policies of most countries in the form of tax benefits and financial subsidies for economic activities and welfare enterprises (Marteau, Ashcroft & Oliver, 2009). The healthcare industry has witnessed a boom in the ‘pay for performance’ where providers are incentivized over and above their usual compensation for work, to deliver high quality, evidence based care (Volpp, Pauly, Loewenstein & Bangsberg, 2009). In view of these programs, policy makers and healthcare scholars have wondered how financial incentives can influence health care recipients to change seeming unhealthy behavior and better utilize preventive health care services (Linnemayr, & Rice, 2016; Loewenstein, Asch, & Volpp, 2013; Volpp, Pauly, Loewenstein & Bangsberg, 2009). Insurance companies have been using incentives in the form of lower premiums and plan benefits to encourage their clients to quit smoking, participate in exercise and other preventive services such as screening programs (Greene, 2007). There remains some difference in opinion regarding the just and permissible use of such incentives without infringing on the client’s freedom and right to equal treatment. However, there have been policy recommendations for governments in various parts of the world to include financial incentives in their welfare spending in the form of conditional cash transfers particularly for the underprivileged to promote what is thought as health and well-being promoting behavior. Mexican authorities initiated the *Oportunidades* in 1998, a

conditional cash transfer scheme where families are eligible to receive cash payments on the condition of their attending a range of preventative health care services and sending their children to school (Fernald, Gertler & Neufeld, 2008). The children's fitness tax credit grants up to 500 Canadian dollars per eligible child to Canadian parents towards enrollment of the children in physical activity programs (Leitch, Bassett & Weil, 2006). At times incentives to health service providers are coupled with incentives to consumer-patients. For example, in Australia where the federal government used this two-pronged approach to dramatically improve child immunization from 56% in 1996 to 90% in 2003 (RACGP Immunization position paper, 2003). Financial incentives from governments for women to have more children, to stimulate population growth, often with covert racial and eugenic underpinnings, have a long history in many developed nations like France (Adler, 2003).

Specifically, for health-related behaviors, Giuffrida and Torgerson (1997) evaluated 11 published studies on the effect of financial incentives on patient adherence to healthcare treatments. Financial incentives, they found, to be more effective than other methods of improving adherence (Giuffrida & Torgerson, 1997). For example, for homeless people with tuberculosis, a \$5 incentive proved to be more effective than peer support (Pilote et al., 1996). Moreover, some have argued that financial incentives tend to be more cost effective than alternative interventions, in that financial incentives can produce better adherence at lower cost (Reiss & Bailey, 1982). Another way to imagine cost effectiveness is to ask the question if the extra adherence achieved via an intervention is worth the extra cost (Torgerson & Donaldson, 1994). Cost effectiveness

of financial incentives can be argued for if substantial treatment benefits are obtained both at the level of the patient and the society or community at large, what is known in economics as positive externalities. A good example is the treatment and prevention of tuberculosis. Poor patient adherence to anti-tubercular drug therapy results in more resource intensive treatment for the individual patient later in the disease cycle and simultaneously increases the chances of development of drug resistant strains of the disease and continued risk of spread to uninfected individuals (Kent,1993). Financial incentives have proven to be feasible and cost-effective in improving adherence in tuberculosis patients (Cuneo & Snider,1989; Pilote et al., 1996). HIV infections' treatment with HAART has similar features to that of tuberculosis regimens: prolonged daily medical regimes, emergence of resistance due to poor compliance and the benefit of suppressing new transmission by effective treatment of those infected. A cost benefit analysis for financial incentives for improved adherence to HAART should consider the positive externalities (benefit to the population, reduced cost of follow up treatment etc.) as in the case of tuberculosis.

When non-adherence is associated with low income, as is often seen in the case of HIV positive patients (McDonnell Holstad, Pace, De & Ura, 2006), financial incentives might also improve equity. When controlling for other contributing factors, financial incentives have been shown to have a greater effect among low income patients (Sutherland, Christianson & Leatherman, 2008). The use of financial incentives in public programs serving these groups may be a relatively inexpensive way to achieve desirable preventive care behaviors. The dearth of studies involving long-term follow-

up, however, means that relatively little is known regarding whether behavior changes persist.

Looking specifically at adherence to HAART, Rigsby and colleagues (2000) found that cue dose training (linking medication taking with individual's daily habits) with cash reinforcement improved adherence (as compared to those with only cue dose training) in a predominantly African American group with history of substance use. However, the improvements were transient and 8 weeks after the cash incentive and cue dose training was discontinued, the adherence in the group regressed back to the baseline levels (Rigsby et al., 2000). Thus, long term financial incentives may be necessary to improve and sustain desirable adherence levels.

A recent multi-site study conducted by El-Sadr and colleagues (2015) found that financial incentives did not increase overall linkage to care or viral suppression (i.e. adherence to HAART, assuming high adherence leads to viral suppression) in HIV positive patients. However, the study recorded significant improvement in viral suppression in certain subsets of study sites. Hospital clinics and smaller sites which had less than 185 patients in care showed substantial increase in viral suppression for patients who were provided the financial incentives compared to those who were not. Moreover, continuity to care increased in community clinics, smaller sites, and sites with higher baseline viral suppression in the presence of financial incentives (El-Sadr et al., 2015). These findings raise the question of why financial incentives work better in some settings (smaller clinics, community clinics, hospital clinics) rather than the rest and how best to implement them. An in-depth understanding of the mechanism of



financial incentives in clinical settings for HIV can help answer some of these questions.

The research on the use of financial incentives for care providers show their efficacy in changing healthcare professionals' practice (Flodgren, Eccles, Shepperd, Scott, Parmelli & Beyer, 2011). However, the evidence from reviews that examined the effect of financial incentives to care providers on patient level outcomes is at best equivocal (Linnemayr & Rice, 2016; Flodgren, Eccles, Shepperd, Scott, Parmelli & Beyer, 2011). There is a need to better understand the mechanics of how financial incentives work in the context of HAART adherence to implement such interventions for the future.

### **Conceptual understanding of Financial Incentives**

The effect of financial incentives on motivation has been researched in the classroom and workplace settings (Deci, Koestner & Ryan, 1998; Frey & Jegen, 2001). A meta-analysis of 128 experiments conducted under laboratory-like conditions found that intrinsic motivation, as assessed by persistence in a task when rewards are stopped, was undermined by the use of rewards (Deci, Koestner & Ryan, 1998). The extent to which these effects are evident when incentives are used to achieve health related behavior change is unknown.

The decision whether to engage in an incentivized behavior is particularly important when the target behavior has the potential to cause harm, as is the case with taking certain medicines. Individuals may change their preferences or priorities over

time and even at any given point they may have competing preferences. In the case of adherence to antipsychotic drugs, for example, an individual may consider the side effects of excessive weight gain and the risk of diabetes vis a vis a reduced chance of a future psychotic episode. Providing incentives may tip the balance in favor of adherence, however, if the full extent of adverse effects is glossed over in the context of short term financial reward, the individual may be ill prepared for their occurrence leading to them blaming and mistrusting the prescribing medical provider. Thus, the question remains how incentives might be offered to facilitate and not erode informed choice.

Finally, offering patients incentives changes the dynamics of an exchange based on trust between patient and doctor to one in which it becomes a financial transaction (Oliver & Brown, 2012; Heyman & Ariely, 2004). Empirical investigation is needed to understand how, if at all, financial incentives alter the nature of patient-medical care provider relationships.

## **Conclusion**

The history of HIV care in the US is one that has raised critical issues of social justice and forced engagement with vulnerable populations. It has challenged the hitherto accepted modes of public health and medical responses to crises in that it has mandated the system to provide speedy and increasingly widespread access to new forms of care and health management. At the current juncture, there are pharmacological agents which promise to improve the lives of those affected with the

virus and at the same time prevent its further spread. For the first time in the history of modern medicine there is a technology that can control and effectively end an infectious disease epidemic not by complete cure or vaccination, but through chronic management with medicines (Deeks, Lewin, & Havlir, 2013) which requires ongoing efforts from both the providers and consumers of the drugs. Hence, it becomes imperative for health and human service providers to come up with modes of making this prolonged engagement with treatment a feasible and sustainable process for all groups of affected individuals (Marrazzo et al., 2014). While one appreciates the barriers to such chronic management (adherence to medical regimes), it is imperative to explore and understand the ways in which certain interventions aimed to improve adherence work with different groups of people. Financial incentive is one such intervention which holds the promise to improve and stimulate long term adherence (Giles, Robalino, McColl, Sniehotta & Adams, 2014; Petry, Rash, Byrne, Ashraf & White, 2012). However, there are several issues with financial incentives with regards to motivation, sustainability and moral concerns regarding its potential corrupting and coercive effects on vulnerable populations (Marteau, Ashcroft & Oliver, 2009). The next chapter reviews some of these issues and provides better context for understanding how to approach the study of such an intervention.

## **Chapter 2: Exploring the debates around Financial Incentives**

### **Introduction**

There is a substantial body of literature which has explored the effect of financial incentives for health care providers: The Pay for Performance (P4P) programs where providers are remunerated in accordance with their performance (Petersen, Woodard, Urech, Daw, & Sookanan, 2006). In the recent years, policy makers have proposed extending financial incentives to patients (a Pay for performance for Patients (P4P4P)) as a more direct way to promote positive health behaviors like adherence to medical advice, smoking cessation and adopting routine physical activity (Volpp, Pauly, Loewenstein, & Bangsberg, 2009). Recent scholarship shows encouraging results with health interventions promoting adherence and linkage to care using financial incentives (Giles, Robalino, McColl, Sniehotta & Adams, 2014; Solomon et al., 2014; Petry, Rash, Byrne, Ashraf & White, 2012). However, there is a gap in our understanding of how these financial incentives can influence behavior. Although a recent work qualitatively explores the role of incentives in adherence (Greene et al., 2017), there has been no systematic study to understand the context specific psychosocial phenomenon that mediates the effects of financial incentives. The major fields where such incentives have been studied are in education, psychology, and work place economics. In an effort to better understand the implications of what financial incentives mean for participants in a clinical setting this chapter reviews some extant concepts and moral debates around the concept of incentives in psychology, education and economic thought.

## **Theories of Motivation**

Motivational Psychology theories hold that external intervention, such as monetary incentives or punishments, may under certain conditions reduce intrinsic motivation to perform certain activities. In 1970, Titmuss in his influential work “The Gift Relationship” claimed that paying blood donors will monetize the socially valued act and will undermine the willingness to donate blood (Titmuss,1970). Thus, a financial incentive for a hitherto voluntary act will reduce the willingness of possible donors instead of encouraging it. Although, the thesis was not backed up by empirical evidence, it garnered a lot of attention at the time. In 1973, Upton validated some of these claims by demonstrating that the rate of donating blood was substantially higher in a group of previous donors that were not offered payment to donate again compared to those who were offered such payments for donating again (Upton,1973).

Psychologists explain this effect by claiming that under a given set of conditions, monetary or external rewards reduce intrinsic motivation. If intrinsic motivation is deemed beneficial, providing rewards for doing something that was previously dependent on intrinsic motivation can prove detrimental to motivation and hence completion of or success in the activity. This indirect negative influence has thus been termed “the hidden cost of reward” (Lepper& Greene, 1978) or “corruption effect” (Deci,1975).

Intrinsic motivation has been defined as the motivation one feels “to perform an activity when one receives no apparent reward except the activity itself” (Deci,1971). Deci, Koestner and Ryan’s Cognitive Evaluation Theory (CET) formalizes the notion of

intrinsic motivation (Deci, Koestner & Ryan,1999). The psychological needs for autonomy and self-determination lead to intrinsic motivation. Rewards are interpreted variously by their recipients, and CET holds that how recipients interpret rewards with regards to their perceived notions of self-determination and competence significantly influence motivation. Thus “events that allow need satisfaction tend to increase intrinsic motivation whereas those that thwart need satisfaction tend to decrease intrinsic motivation” (Deci, Koestner & Ryan,1999). CET proposes that rewards can be interpreted by recipients primarily as controllers of their behavior or, alternatively, as indicators of their competence (Deci, Koestner & Ryan,1999). When rewards are thought to control behavior, they are perceived to thwart need satisfaction. Individuals feel that their reasons to perform a task lies outside their felt need (external locus of causality), i.e. externally controlled by the incentive of the reward, leading to diminished intrinsic motivation (Decharms,1968). Whereas when rewards inform individuals of their abilities, they satisfy the need for self-competence, ultimately boosting intrinsic motivation.

**Crowding out phenomenon.** Economic theory has integrated aspects of CET to formulate theories of crowding in and crowding out of motivation. Simply put, crowding out refers to the possibility of reducing (crowding out) of motivation or of increasing (crowding in) motivation to perform a task with the introduction of incentives (Frey & Jegen, 2000). As such, motivational crowding out theory goes against the grain of traditional economic logic of increased supply with the introduction of incentives (Frey & Jegen,2000). While much of standard economic thinking assumes

that motivation for most economic activities comes from outside the person (economic gain, securing economic well-being) psychology has been more interested in tracing the locus of motivation within the person. Motivational crowding theory is an attempt to bridge this gap.

Standard economic principal agent theory postulates that external intervention improves performance by imposing higher marginal cost on non-performance or, reversely increasing the marginal gain on performance (Alchian&Demsetz,1972; Fama & Jensen,1983). This is called the relative price effect of external interventions. Intrinsic motivation is assumed to be either absent or an exogenous constant. Cases, where external intervention increase intrinsic motivation, the marginal benefit of performing is higher (the *crowding in* effect). However, there may be situations where the external reward reduces intrinsic motivation by making individuals feel less in control of their actions as explained earlier. In these situations, external interventions crowd out intrinsic motivation. Usually both the relative price effects and the crowding out effect simultaneously occur in a situation; thus, external intervention has two opposing effects on the performance of an individual. How the external intervention in the form of incentives will affect the task performance depends on the relative size of the countervailing effects of the relative price effect and the motivational crowding out phenomenon.

**Empirical evidence.** Social Psychologists have gathered an impressive body of evidence in the field of intrinsic motivation. In an authoritative meta-analysis, Deci , Koestner and Ryan (1998) examined studies that looked at the effect of external

reward on intrinsic motivation. Intrinsic motivation as assessed by “the degree to which participants return to and persist at the target activity during a free choice period subsequent to the experimental phase” (Deci, Koestner & Ryan, 1998) and by self-reported interest in the target activity. The researchers concluded that external rewards (whether contingent on engagement with the activity, completion of the activity or performing well at the activity) significantly undermined free-choice intrinsic motivation. Furthermore, engagement and completion contingent rewards were also significantly negatively correlated with self-reported interest. On the other hand, positive feedback tended to increase both the free choice behavior and self-reported interest measures of intrinsic motivation. Frey and Jegen (2001) reviewed the extant literature to find empirical support for motivational crowding out and crowding in theory in the field of economics. They claimed that there exists strong empirical support for such theories based “on circumstantial evidence, laboratory evidence by both psychologists and economists, as well as field evidence by econometric studies” (Frey & Jegen, 2001).

Other researchers have found that work place financial incentives may positively affect the quantity of performance but not the quality (Jenkins, Mitra, Gupta & Shaw, 1998; Jenkins, 1986). Indeed, what Deci has simply described as intrinsic motivation is difficult to operationalize in real life situations where there is usually a complex web of internal and external causes for an action. Although behavior change based on intrinsic motivation is deemed superior (Ryan & Deci, 2000) and more durable than those prompted by external reward, it is often difficult to ascertain exact genesis



and pathways for motivation for initiating a behavior change. Neurological mapping studies have found overlapping pathways in research participants performing simple tasks under different motivational conditions described as intrinsic or extrinsic (Lee, Reeve, Xue & Xiong, 2009). Qualitative work on pay for performance for providers in primary care practice has shown financial incentives to have little detrimental effect on the internal motivation and moral urges of primary care physicians (Mc Donald et al.,2007).

### **Questions for the clinical setting**

What remains to be explored is how questions of intrinsic motivation and motivational crowding out play out in the clinical setting especially with regards to adherence to medication. The research described earlier has been conducted mostly in classroom and workplace settings and have been extrapolated by proponents of financial incentives to the milieu of medical care. Adherence to medication that can potentially sustain a healthy life cannot be simply described as a task that merely has rewards in terms of self-fulfillment and is entirely intrinsically motivated. While being alive and enjoying, good health is often an end in itself, individuals may have a host of other, somewhat external reasons for staying healthy. They may want to be able to work to provide for themselves and dependents, they may wish to be able to emotionally support others, they may desire active engagement in communities as a way of fulfilling civic and communal duties. All these goals can be deemed as external rewards for engaging in the task of adherence to life saving, long term medication. Financial rewards in these setting can be deemed as another external reward that can further

motivate adherence. Moreover, while it is intuitive that intrinsic motivation may play an important role in shaping behavior change especially with regards to long term medical adherence and self-care, the exact dynamics of motivation, its sustainability and manifestation as behavior change in the presence of financial incentives need further explication before theoretical models can be developed. Qualitatively understanding motivation and the external incentive's role therein, from the perspective of the participant is an important first step in that direction. A recently published study by Greene and colleagues was the first one to explore qualitatively the role of financial incentives on adherence to HIV medication (Greene et al., 2017). Their results describe some of the benefits (emotional, financial, health related) of incentives, but further work is needed for more in-depth understanding of the issues and to develop middle range theories which will help in implementation of incentive based programs in health care settings.

**Debates about patient autonomy.** A common concern expressed with regards to the use of financial incentives in the clinical setting, is the loss of patient autonomy (Marteau, Ashcroft & Oliver, 2009). Cognitive evaluation theory and motivational crowding theory can be used to explain this concern. As described earlier, external rewards can be perceived to thwart need satisfaction that comes from engaging in a behavior for its own sake. Individuals may be led to believe that they no longer feel empowered to do a task but do it for the sake of the reward. The locus of control moves from within their own desires to that of the external stimulus of the reward. Patients may perceive this loss of control as a loss of autonomy, or an inability to act as one

truly wants to. Some professionals have long opposed payment to patients for adhering to anti-psychotic drugs because it is thought to impair patient autonomy and attenuate personal responsibility (Claassen, 2007). Using money to force patients to act in ways that may be at variance with their wishes is considered paternalistic at best and coercive at worst.

An alternate perspective emerges by considering how our actions are often not aligned with our desires. We often fail to act in ways that in retrospect we most prefer (Frankfurt, 1988). Many individuals may prefer to eat healthier and many smokers would rather not smoke when they think about long term consequences. However, immediate satisfaction of desires prompt individuals to act otherwise. Thus, there is a discrepancy between the first order desires (those individuals act on) and second order desires (those individuals would have preferred to have acted on). External rewards may be thought to help individuals closely align their actions (first order desires) with their actual preference (second order desires) and thus incentives can be deemed promoting patient's autonomy rather than undermining it. Financial incentives are thought by some to be a "nudge in the right direction" (Linnemayr & Rice, 2016; Thaler & Sunstein, 2009) while others may continue to regard them as "an unacceptable shove" (Marteau, Oliver & Ashcroft, 2008).

Analogous concepts from economic theory also help build a case for financial incentives. It has been long maintained that people do not always think or behave in a rational way and are often not aware of or in control of the myriad factors that influence their behavior. Similar to the above mentioned first order desires, individuals are often

more influenced to act to maximize immediate gains and minimize immediate losses rather than adequately weighing long term consequences. This attitude is termed present bias (Kamenica, 2012; O'Donoghue, & Rabin, 1999), and for behavior change intervention it supports providing immediate rewards for targeted behavior change. Financial incentives, can by this argument, satisfy present bias and provide instant gratification and reinforce the desired behavior where individuals experience long term benefits like symptom free days and good health along with the instant satisfaction of earning the financial reward. Proponents of external rewards have asserted that providing the “carrot” helps individuals initiate a change and enables them to subsequently consolidate the gains and take ownership about maintaining that behavior (Linnemayr & Rice, 2016; Dolan, Hallsworth, Halpern, King, Vlaev, 2010). It is useful to align environments and circumstances, as with the provision of rewards, to help people make better health choices (Klein & Karlawish, 2010). Thus, external rewards are not inimical to patient autonomy but support it in meaningful ways as does health education and better access to services.

**Doctor patient relationship.** Closely linked to the concerns about loss of patient autonomy if financial rewards are introduced in the clinical settings, are doubts about its possible detrimental effect on the doctor patient relationship. The relationship between the doctor and the patient is assumed to be one of implicit trust: the patient trusting the doctor to act in their best interest and the doctor requiring that the patients cooperate in order to achieve the shared therapeutic goals (Pearson, & Raeke, 2000). There lies an element of shared responsibility that transcends the financial transactions

between the recipient and the care-provider. Paying patients to follow their doctor's advice introduces a deleterious transactional aspect to this relationship. Opponents of financial rewards claim that paying patient to do what their doctor asks them to (such as taking the prescribed medication) tantamount to bribery and or coercion (Oliver & Brown, 2012; Marteau, Ashcroft & Oliver, 2009). Such interventions serve to undermine the relationship of trust and impair long term outcomes of enduring therapeutic alliance between clients and providers.

As discussed earlier, incentives can be re-conceptualized as benign and effective persuasion rather than bribery or coercion. If designed with the insight of the providers, financial rewards can aid the therapeutic alliance and help the patient better align her goals with that of the provider who is assumed to act in the patient's best interest. Moreover, there are several extant programs where providers are incentivized for favorable patient outcome over and above their usual compensation. Initial research in these settings have shown no obvious detrimental effect on the doctor patient relationship or the moral impulses of providers in these settings (Mc Donald et al., 2007).

It is useful to remember here that the doctor patient relationship, however idealized, is often marked with a power imbalance and uneven information sharing. Studies on adherence to HIV medication and other chronic medication have repeatedly recommended an open and inclusive approach between the doctor and patient where they share information and come up with common goals (Chesney, 2003; Ickovics & Meade, 2002). Any clinical interventions (with or without financial incentives) need to

be aware of these concerns about power imbalance and incomplete communication between provider and client.

**Financial incentives and notions of fairness, equity, and justice.** Finally, many people object to the use of financial incentives for patients on grounds of fairness. The question being, is it fair to pay some people to do something that others do without being paid? (Marteau, Ashcroft & Oliver, 2009; Volpp, Pauly, Loewenstein & Bangsberg, 2009). Also, is it not one's own responsibility to ensure one's own well-being? How to justify the use of public funds to ensure healthy behavior for those who fail to take care of themselves? Public opinion in the developed western economies usually supports the view that individuals are responsible for their own health and well-being and hence should personally bear the costs of self-inflicted ill health (Dolan, Hallsworth, Halpern, King, Vlaev, 2010). However, research in causation of health and illness especially about personal responsibility have made strong arguments for taking a different perspective. While people do make individual choices regarding their health (whether to smoke, what to eat, practicing safe sex, adhering to prescriptions), they are almost always deeply influenced by the socio-economic contexts they live in (Berkman, Kawachi & Glymour, 2014; Wikler, 1987). Health outcomes are social issues inextricably linked with questions of human rights, justice, equity, and fairness (Hudon et al., 2016; Dworkin, 1981; Wikler, 1987). If one subscribes to the view that health is a social justice issue, financial incentives for adherence to HIV medication, especially among under privileged groups (which consist of a disproportionate number of people of color) can potentially balance out some of the extant structural inequalities and

promote equity and justice. Moreover, incentive programs can be more effective to produce desirable outcomes with disadvantaged or vulnerable populations (Jochelson,2007).

Having said the above, whether or not public funds should be used to improve health outcomes of a community can be answered from several angles. Firstly, it deals with the basic question about the expectations from a welfare state and what it may or may not do for its citizens. Neoliberal ideas support increased retraction of state sponsored services and encourage market based insurance that signal personal responsibility (Harvey, 2001). It is assumed that a free market will enable most citizens to seek gainful employment and then, they can purchase health benefits through market based insurance. The state should not encourage dependency and disincentivize gainful employment by providing social assistance in the form of welfare benefits, cash transfers or free or subsidized health care services. On the other end of the spectrum socialist ideas have championed the state as the ultimate arbitrator of welfare and the sole provider of publicly funded welfare benefits. Free for all health services, either entirely owned and managed by the government or paid for by public money, is the hallmark of socialist welfare states (Field & Cockerham, 2014). Most developed nations of the West fall somewhere in this continuum (Esping-Andersen, 1990) and many like Canada and the UK have nationalized health services while the US still relies heavily on the private sector for health care. If there is a consensus regarding spending public money for health care for all, financial incentives which can improve health outcomes may find ungrudging support. In countries like the UK, which has a nationalized health

system for the last sixty years, public opinion surveys have revealed that while most people want individuals to take responsibility for their own health, they also see the government's efforts to promote health as an important part of the equation (Lynagh, Sanson-Fisher & Bonevski, 2011).

With advent of the Affordable Care Act, the US has moved towards a more publicly funded health insurance system where the risk of ill health is pooled more widely among the well off and historically well insured citizens along with the less privileged, often less healthy and hitherto uninsured groups. Though recent legislation may roll back many of the provisions of the Affordable Care Act, one may still expect a change in the profile of people with insurance as compared to the last couple of decades. In such a situation, financial incentives that promote healthy behavior and potentially reduce future healthcare spending may make sound economic sense, even if one were to disregard to social equity and human rights aspect of the problem. In case of HIV /AIDS which has huge costs (in healthcare provision, along with loss of productivity and hence economic output of those afflicted) an intervention which can possibly help mitigate these costs has an intuitive appeal. More specifically the intervention (like improved adherence to HAART with a financial incentive) not only improves the lives of those infected with the virus but prevents the transmission of the virus. Financial incentives for such outcomes can be seen as benefiting both the individual who is infected along with large groups of people at risk for new HIV infection. In this case paying the patient to remain healthy accrues huge benefits to the patient along with the uninfected individuals.



It is also important to remember that public funds are already being used to derive public health benefits through anti-smoking campaigns and HIV/AIDS awareness programs and people usually do not object to these spending. While health education and awareness along with screening programs can potentially improve the health outcomes for a population, financial incentives may in certain cases be a more direct and efficient use of resources to change certain behavior.

Studies on patients' perspectives on incentives have been few (Greene et al., 2017). The ones that have been undertaken show that it is important how questions are framed and usually people are more likely to support a positive reward that encourages healthy behaviors rather than endorse punitive measures to correct unhealthy ones (Linnemayr & Rice, 2016; Long, Helweg-Larsen, & Volpp, 2008).

### **Current study**

Financial incentives have been understood in the context of various theories from behavioral economics and psychology. Whether financial incentives work varies with the population with and the conditions under which they are implemented. Although studies have found that financial incentives may be effective in clinical settings with issues of adherence, there has been inadequate attempts to understand and theorize the process through which incentives works under conditions of clinical medical care. Furthermore, financial incentives for behavior change in health and human services raise moral questions around coercion, undermining of patient autonomy and subversion of the ideal therapeutic relationship. However, financial

incentives can be viewed as effective, albeit small, instruments in trying to reverse the deleterious impacts of socio economic marginalization of certain vulnerable groups as we try to promote healthy behavior in them. Given this context the present study examined the phenomenon of financial incentives and its role in promoting adherence to HAART medication in a group of resource poor people living with HIV/AIDS. The next chapter describes the methodological approach used to study the phenomenon.

### **Chapter 3: Methodology**

As described in the earlier chapters, financial incentives in the context of adherence to medication, is an understudied phenomenon. Specifically, there is a lack of understanding of the psychosocial processes that influence patients' reactions, acceptance and ultimate effectiveness of financial incentives that tend to encourage adherence to medication in chronic conditions like HIV infection. The current study aims to fill that gap by exploring the phenomenon of financial incentives in the context of adherence of PLWHA to HAART regimens.

#### **Understanding adherence using Constructivist Grounded Theory**

Grounded theory is a methodology that seeks to construct theory about issues of importance in peoples' lives (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). It does this through a process of data collection that is often described as inductive in nature (Morse, 2004), in that the researcher has no preconceived ideas to prove or disprove. Rather, issues of importance to participants emerge from the stories that they tell about an area of interest that they have in common with the researcher. The researcher analyzes data by constant comparison, initially of data with data, progressing to comparisons between their interpretations translated into codes and categories and more data. This constant comparison of analysis to the field, grounds the researcher's final theorizing in the participants' experiences.

Constructivism is a research paradigm that denies the existence of an objective reality, "asserting instead that realities are social constructions of the mind, and that

there exist as many such constructions as there are individuals (although clearly many constructions will be shared)” (Guba & Lincoln, 1994). Constructivist grounded theory as expounded by Charmaz (2006) acknowledges constructivist limitation while striving to create new theoretical understanding of understudied phenomenon by employing grounded theory methods.

A constructivist grounded theory approach is most suitable for exploring areas that have not been previously studied or theorized. It helps researchers to come up with new and interesting insights and stimulates the creation of new, context specific middle range theories (Oktay,2012). Hence this method is particularly helpful in cases where there is no preexisting theory as in case of financial incentives and adherence. However, a constructivist approach to grounded theory acknowledges that researchers are not blank slates but come with their disciplinary foci and personal political biases. While the focus of this method is to look at data with a fresh view keeping aside preconceptions, constructivist grounded theory allows for sensitizing concepts to inform the analysis (Charmaz,2006; Bowen,2006). The methodological imperative is to state these ideas clearly and use them only in the context of gathered data. The ideas should not be used to shoe horn the collected data into neat categories, but the researcher should only use the sensitizing concepts as categories of analysis if sufficient data emerges to support those ideas.

In trying to understand the role of financial incentives on adherence to medication, I used a constructivist grounded theory approach. The sensitizing ideas of motivation,

coercion, patient autonomy, patient provider relationship (as described in chapter 2) were sensitizing concepts in my analysis.

### **Research question**

Using a qualitative, constructivist grounded theory approach the present study aimed to answer the following question:

*How does the provision of financial incentives affect the process of adherence to anti-retroviral medication in individuals with HIV infection?*

### **Study settings**

The research was conducted at Housing Works (HW), a large advocacy-based HIV service organization based in New York City. It is intimately involved in local, state, and national housing and HIV policy. This community-based HIV service organization was founded in an activist tradition of HIV/AIDS advocacy. Its current primary programming focuses on HIV related healthcare and housing programs. In 2013 Housing Works initiated the Viral Load Suppression (VLS) program with an aim to achieve viral load suppression in more than 80 % of their HIV positive clients. It sought to achieve this aim by promoting adherence through the provision of quarterly financial incentives to participants who have viral loads below a certain threshold. Additionally, the VLS program provides access to adherence support groups, improved case management with a focus on adherence to anti-retroviral medication and services for text reminders and directly observed therapy. Each client has the option to enroll in

one or many of these VLS services. For example, a client may choose to attend adherence support groups, get enrolled in the text message reminder system and if they and their providers still feel that more intensive support is needed to help them with adherence, they can be enrolled in directly observed therapy (DOT), where the patient-client takes either all or some of their medication under direct supervision of a nurse. The VLS program aims to provide the client with a tool box of services that they can employ to improve their adherence. The current study is a part of a larger study evaluating the VLS program to identify the best practices and processes of organizational change that the program is expected to bring.

### **Ethical considerations**

The evaluation study of the VLS program, of which the current study is a part, has been approved by the Institutional Review Board of the University of Pennsylvania. Informed consent was obtained from every client at the time of enrollment in the program. Clients consented to participate in the research evaluating the study and signed consents forms to that effect. At the time of the qualitative interviews the nature and purpose of the interview was explained to each participant and informed consent was obtained verbally and then on audio recording. Participants received \$20 gift cards after each interview to compensate for their time and were issued metro cards to help them with the transportation. These cash and transportation compensations are in accordance with the policies of Housing Works and was provided by them from their research funds.

Efforts were made to protect the privacy of the participants. Upon conclusion of this study and subsequent analyses approved by the IRB, the original recordings will be destroyed. Names and identifying markers were removed from the transcribed interviews and no personal identifying information (like names) was mentioned in any report on the findings from the study.

### **Sampling Procedures**

Participants were recruited from the list of clients who have been enrolled in the VLS intervention program. I shortlisted possible participants in consultation with agency personnel like case managers, program directors, medical providers, and nursing staff. These candidates were contacted through their case managers and initial agreement for participation was sought through the case managers. I worked with the case manager and the participant to identify convenient time and location for the interview. The interviews were held at the various agency locations of Housing Works across New York City.

Sampling was continued until theoretical saturation was reached. Theoretical saturation is defined as the point in qualitative research when new concepts stop emerging from new interviews (Guest, Bunce, & Johnson, 2006). While other sampling techniques target for certain fixed sample size, theoretical sampling is data driven (Charmaz, 2006). The aim of such qualitative research is not to produce widely generalizable findings, justified by a large or representative sample size. Instead, such an approach explores new ideas and brings to light new and more nuanced

understanding of a phenomenon. Theoretical sampling requires the researcher to be intimately involved in data collection process. The researcher needs to identify when new concepts stop emerging and to this end must keep detailed memos of the collected data and engage in simultaneous analysis and collection of new data. A final sample of 30 individual interviews was recruited for this study.

**Inclusion and exclusion criteria:** For participating in the study the clients met the following criteria: a) be over the age of 18 and be eligible to provide informed consent, b) be enrolled in the VLS program c) understand and speak English. Individuals under the age of 18 and those unable to provide informed consent and not comprehending English were excluded from the study.

### **Data collection**

**In depth interviews.** The study investigator, that is I, conducted in-depth, semi-structured qualitative interviews with VLS program participants. Interviews lasted approximately an hour and were audio-recorded (refer to Appendix 1 for interview guide). Interviews were held at a location and a time convenient to the participant, primarily at various Housing Works offices/clinics across New York City. The interviews were completed within a period of approximately four months from end of May 2016 till the end of September 2016.

At the beginning of each interview, a demography /short history sheet was filled out by the interviewer. This recorded the participant number, age, gender, preferred pronoun, race, ethnicity along with details like date of HIV diagnosis, housing history,



mental health history and history of incarceration (refer to appendix 2 for demography sheet). The data thus collected helped us gain some baseline ideas about the participants and the results are presented alongside the analysis of the interviews in the next chapter.

Simultaneous data analysis guided and shaped the data collection process and focus of interviews. The major focus of the interviews was to explore the participant's experience with the VLS program, in particular how they view and are affected by the financial incentive program in their effort to adhere to daily antiretroviral medication regimens. An interview has been described as a directed conversation (Lofland & Lofland, 2006). An intensive interview allows the researcher to explore "a particular topic with a person who has had the relevant experience" (Charmaz, 2006). The in-depth nature of interviews can facilitate each participant to uniquely describe and relate their particular experience with a phenomenon. The questions and probes provided by the interviewer can encourage participants to reflect upon their experience and describe it in a detailed way that is rarely possible in everyday conversations. The interviewer's role is to listen attentively, record observations during the interview in the way of notes and memos, and constantly encourage the participant to respond to and elaborate on the probes and questions that she puts to them. During an in-depth interview, the interviewee should do most of the talking, while expert interviewers can unobtrusively direct the interviewee to answer the relevant questions and keep them from digressing. Having said that, digressions can often provide valuable insights to hidden processes and hitherto unexplored concerns. The exact manner in which a particular interview

unfolds depends on the context, the scope of the research question and the rapport established between the interviewer and interviewee.

Grounded theory seeks to propose a fresh understanding of the phenomenon under study. It proposes to achieve this by treating data as it is and not forcing them into pre-fixed categories or constructs. However, constructivist grounded theory allows the researcher to acknowledge certain pre-conceived ideas or disciplinary focus to shape the way questions are asked and data is analyzed. These ideas or sensitizing concepts can guide some of the research, however they need to be substantiated by the collected data and the data must not be forced into these categories or themes. Following this concept, the in-depth interview looked out for certain themes or ideas that have been described in chapter two. The interviewer sought, among other things, to elicit the participant's view on motivation, feelings of being coerced or bribed, relationship with service providers, ease of integration into lifestyle with respect to adherence and the financial incentives of the VLS project. The interviews were audio recorded and then transcribed by me during the period of data collection. These transcripts became the primary data for the results presented in this study.

**Focus groups.** In addition to the individual in depth interviews, I conducted one focus group with seven VLS participants. The focus group lasted for one and half hours and was audio-recorded, and then transcribed. They were moderated by me and one other researcher from the IRB approved research team. The focus group was conducted before the data collection through in-depth interviews began, as preliminary ground work to gain a sense of the general issues that the participants were concerned with.

They aimed to elicit the participants' views on adherence, challenges to adherence and the processes in which participating in VLS program is affecting those issues. The data from the focus group helped me design the interview guide for the study. Focus groups can serve to elicit different aspects of the process that individual interviews fail to reveal (Stewart & Shamdasani, 2014). They are especially useful in obtaining group level opinions and perceptions of phenomenon (Charmaz & Belgrave, 2002). In the context of a community based service provider organization like Housing Works, focus groups can be especially expedient in exploring community level processes and opinions that affect participation in and outcomes of an invention.

**Field notes.** Fieldnotes document information, impressions and relevant cues for the researcher (Corbin & Strauss, 1990). These hand-written notes recorded the impressions, incidents and feeling during the process of interviews, focus groups and other interactions in the agency settings. Field notes captured what the recorded interviews did not, for example, if the participant was showing the interviewer some object, or how the interviewer gauged the mood of the participant as they were discussing an issue. Field notes were analyzed alongside the interview transcripts as primary data.

### **Qualitative Data Analysis**

I transcribed the in-depth interviews and focus groups. The online software Dedoose was used in coding and analyzing the data (Version Dedoose,2013). As mentioned earlier, data collection and data analysis was a simultaneous process. I

looked at the initial 10 interviews and the codes and themes arising from this analysis was subsequently used to direct the later interviews. The new interviews thus collected contributed to further analysis and refinement of conceptual categories. Through this constant interaction between data analysis and data collection, theoretical abstractions true to the collected data emerged (Charmaz, 2006).

Constructivist ground theory was used in the qualitative data collection and analysis. Charmaz's (2006) conceptualization of grounded theory emphasizes the role of interpretation and meaning and the notion that meaning is co-constructed by the researchers and the interviewer and is not simply "discovered". Specifically, she highlights that grounded theory is an interactive and interpretative process, in which the researcher is conceptualizing and constructing the participants (re)construction of reality (Charmaz, 2006). Researchers are not objective observers; rather they are a valuable part of the research and interview process and outcome (Guba & Lincoln, 1994). Unlike the initial conceptualization of Glaser and Strauss, Charmaz specifically argues that "...neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We construct out grounded theories through our past and present involvements and interactions with people, perspectives, and research practices" (Charmaz, 2006). In addition, grounded theory should not be utilized as a formula to collect and analyze data, but rather an emergent method. A constructivist grounded theory methodology was used in this project as I was interested in exploring how financial incentives influence or make an impact of patient's decision to adhere to medication and their life choices around these decisions. The constructivist caveat

signals that ideas reviewed from existing literature, like motivation, provider patient relationship, regimen complexity had some influence on how I made sense of the emerging data. However, the objective was to move beyond these ideas and evolve new theory to facilitate a better understanding of the phenomenon.

First, I read the transcripts, without coding the data which was followed by initial coding. Coding is the process of categorizing and naming segments of data (Charmaz, 2006). Initial coding helps the researcher to be grounded in the data. This involves either a line by line or incident by incident coding of the data. Subsequently these initial codes were compared between the different interviews. This comparative exercise helped clarify new codes or categories and ultimately lead to the emergence of themes and patterns (Charmaz, 2006). Through this process of comparison and refinement, initial codes evolved into focused codes. Diagrams and notes were used to form conceptual audit trails (Charmaz, 2006). Specific attention was paid to the phrases or words participants have used in the interviews (the next chapter will detail some of those, also refer to appendix 3: notes from research journal). Charmaz describes these phrases to be in vivo codes in that they are the “symbolic marker of the participant’s speech and meanings” (Charmaz, 2006). These in vivo codes help the researcher to stay grounded in the actual data and away from preconceived concepts, by using the participant’s actual terminology to develop categories. Proceeding from focused codes, categories were developed from the data by clumping focused codes together. In the final level of analysis, theoretical coding was used to establish connections between the categories developed from the initial coding. Conceptual diagrams were created and

refined through this process (Figure 1 in chapter 4 on page 45). Throughout this analytic process memo writing helped organize ideas and expedite the process of transitioning from initial codes, to focused ones, therefrom to categories and finally to abstract theoretical constructs. Excerpts from the research journal is available in Appendix 3 , where examples of the process of transition from primary to focused and then to theoretical coding is documented.

**Establishing Rigor.** Establishing rigor is an important component of grounded theory that helps to ensure quality (Padgett, 2008). A few strategies were employed to enhance research rigor. First, research decisions were methodologically transparent (Charmaz, 2006; Oktay,2012). All details regarding coding and category development was noted. I maintained a researcher journal for the purpose of writing every step in the research problem and noted any concerns like logistics, ethical issues and theoretical problems during the process of data collection and analysis. This process of maintaining an “audit trail” (Padgett, 2008) helped map the course of developing concepts and themes and strove to clarify all the interim steps between data collection and final theoretical conclusions (refer to appendix 3).

Member checking were planned to provide participants with the opportunity to comment and contribute to the findings (Creswell, 2007; Padgett ,2008). However, due to logistical challenges, at the time of writing this report we had not been able to conduct any member checks. We plan to do them in the near future in consultation with the agency. Triangulation of the data using interviews with the field notes and focus groups was undertaken to ensure validity of the findings (Oktay, 2012). Furthermore,

throughout the process of data collection and analysis, I discussed the process with my advisors and research peers. This form of peer debriefing (Padgett,2008) helped clarify ideas and ensure that the analysis remains true to the data obtained.

## Chapter 4: Results

### Introduction

The financial incentive along with the other supportive services reinforced, for some participants the motivation for better adherence to medication and improved their attempts to ensure their health. Some participants felt, more than ever before, supported in their medication adherence issues and they sought to optimize these resources to seek better outcomes for themselves. Psychologists working on financial incentives have theorized that external rewards may undermine intrinsic motivation of participants to engage in an activity (Deci, Koestner & Ryan, 1999). Such an undesirable reliance on these external stimuli results in less motivated participants and their output/outcome may ultimately suffer in the context of these incentives. However, proponents of financial incentives point out that external rewards may sometimes help individuals to better align their immediate actions to longer term goals (Marteau, Ashcroft & Oliver, 2009). External rewards may help participants to perform the difficult task at hand which can yield beneficial long term results. A qualitative study of the Viral Load Suppression (VLS) financial incentive scheme with the clients found support for the latter view. In this chapter, the results of the study in the context of a model for motivation through financial incentives that was developed from the research findings are presented.



## Participant Characteristics

Our participants were drawn from the list of clients provided by housing works and were contacted through their case managers. Table 1 below summaries the demographic profiles of the participants. Out of a total of 30 participants, 17 identified as women, 10 identified as men and 3 identified as transgender women. Their ages ranged from 35 to 75 years with mean age of 50.9 years. African Americans comprised 40% (12), Blacks made up 36.6% (11), Hispanics accounted for 3.33% (1), Latinos made up 10% (3), Mixed race comprised 3.33% (1), and Whites made up 6.66% (2) of the study sample. 73.33% (22) of the participants had a history of substance use, and 40 % (8) reported a mental illness history. About 63.33% (16) reported a history of incarceration. The number of years since HIV diagnosis ranged from 9 months to 22 years with a mean of about 8.6 years. Apart from one man who reported independent income, the rest reported being reliant on welfare benefits, though we did not ask the details of income and the different benefits that they accessed.

**Table 1**

*Participant Characteristics*

	N=30	(%)
<b>Gender</b>		
Woman	17	56.67%
Man	10	33.33%
Transgender Woman	03	10%

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**Age**

35-45	11	36.67%
46-55	09	30%
56-75	10	33.33%

**Race**

Black	11	36.67%
African American	12	40%
White	02	6.67%
Hispanic	01	3.33%
Latino	03	10%
Mixed	01	3.33%

**Sexual Orientation**

Heterosexual/Straight	16	53.33%
Homosexual/Gay	09	30%
Bisexual	04	13.33%
Other	01	3.33%

**Years since HIV diagnosis**

0-5	12	40%
6-10	09	30%
11-20	08	26.67%
>20	01	3.33%

**History of Incarceration**

Yes	19	63.33%
No	11	36.67%

**History of Substance Use**

Yes	22	73.33%
No	08	26.67%

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**History of Mental Illness**

Yes	12	40%
No	18	60%

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**A Theory of the Effect of Financial Incentives on Adherence**

The aim of this study was to develop a middle range theory employing a grounded theory approach, to understand the role of financial incentives on adherence to HAART medications in HIV positive people enrolled in an adherence intervention program (The Viral Load Suppression program or VLS) at Housing Works. We found that financial incentives shaped adherence to HAART by influencing motivation to adhere to the medication, as well as the barriers and facilitators to adherence present in the individuals and their environment (Figure 1).

Motivation has been the major focus of research on incentives, however the components or processes through which motivation works especially in a clinical setting has not been well theorized. These results suggest that there were symbolic and material aspects to the effects of financial incentives on motivation. Facilitators of and barriers to adherence were both influenced by financial incentives and the facilitating factors in turn influenced the effect of the incentives. That being said, not all barriers or facilitators were equally influenced by incentives. The factor of motivation was also

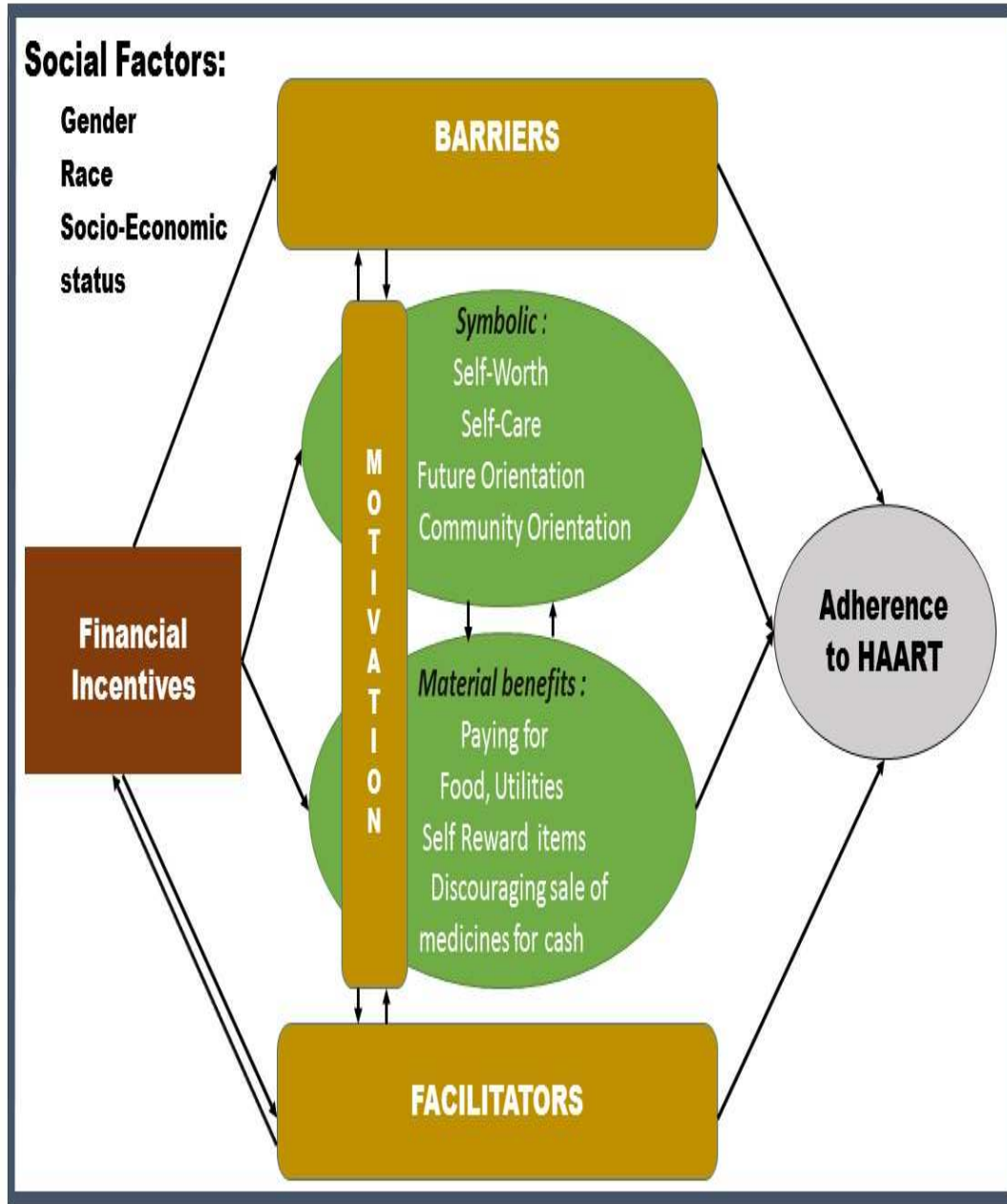


Figure 1. Proposed model for the Effect of Financial Incentives on Adherence to HAART.

heavily influenced by the facilitators and barriers to adherence and motivation itself, in turn, had some effects on the effect of the facilitators and the barriers. Figure 1 depicts the proposed model. This is an initial suggestive model where the arrows indicate possible connections and directions of influence. The extent of these connections and interactions are described qualitatively in this chapter.

### **Motivation**

The payment of incentives for adhering to health promoting behaviors sent out complex messages. While it has been argued that the payment of incentives can be thought of as coercion and bribery, our participants differed with that view. The incentives motivated them, beyond the usual practice of adherence counseling and support, to adhere to the recommended HIV medication. They felt motivated to enroll in the program and take better care of themselves.

This study proposes that the motivation comprised of two distinct but interrelated processes, one of symbolic meaning derived from the reward and the other being the actual material benefits obtained from the cash incentive. Furthermore, under symbolic meaning we identify four, separate yet overlapping, processes: deriving meanings of self-worth, stimulation to self-care, orientation towards community care and imagining possible futures.

**Symbolic Motivation: Self-worth.** The VLS program, with the Incentive and other special adherence focused services, was generally well received by most participants. For some clients, the implementation of these new and improved services

(directly observed therapy, adherence groups, and text message reminders) along with the provision of financial incentives signaled that the providers were concerned about their adherence and general well-being issues. The concern on the part of the providers were interpreted, by some, to mean that they, the clients, were worthy of that concern. This in turn translated to a greater sense of self-worth among some participant clients.

One client mentioned how this program was a response to her own felt need and how it has served that need.

I was horrible with my medication, always horrible. Then I thought that's why they have this program because I am not the only one. This program gives me all the things I need. I am thinking about my medicines more, I am less likely to forget about them these days. I have doctors and nurses talking to me about it. My case worker checks in with me about my meds. I get regular blood works and know my results, my CD4 s. I am working with this program to become undetectable. In the end the incentive comes along and that feels good. (Black woman, 54 years)

She admits that in the past she had trouble with taking the medication regularly. The intervention, according to her, has responded to that need. She described how the program helped her focus on her adherence with all the major care provider groups talking about the issue. Her being enrolled in the program, which requires regular clinic visits and quarterly blood examinations, provides her feedback on her efforts at adherence. She feels a sense of partnership with the service providers in their common cause of her adherence and well-being. The incentive provides an additional reward over and above the services and attention, which overall, she regards as a satisfying experience.

Another Black woman echoes the sentiments expressed by the earlier participant. She describes her views on the incentive in the following manner:

A 100 dollars to save your life? That's a no brainer. It gives you great incentive to take your medication. It is like getting rewarded for doing the right thing. It is great, I feel very happy to be in this program. I think I am special and I deserve the care and the love of all these people. I will not let them down. I tell myself that you deserve to be healthy and now you can be healthy and live your life. (Black woman, 55 years)

We see how for this participant being a part of the intervention has improved her sense of self efficacy towards her adherence behavior. She clearly mentions how she feels that she deserves to be a part of the program, how she feels worthy of their care and how it prompts her to do her own part and feel more confident of her abilities to take care of her own health. Self-esteem or self-worth in this case is influencing self-efficacy. Though we cannot claim any causal links between the two from this study, it is certainly worth noting the association for future research.

The most succinct remark about how this intervention in general and the financial incentives in particular, has affected-self-worth perceptions came from a 55-year-old African American man. When asked to describe how he feels being a part of the VLS program he said, "I feel like a White Mama." He went on to explain that for the first time in his life he feels truly cared for. Not only does he have access to improved services but that 'someone' cares enough to reward him with 100 dollars for staying healthy. The reward money indexes a sense of worth. The actual amount was not perceived as a mere monetization of that worth but signaled a commitment on part of the providers to care for the health and well-being of the participants, who are

economically underprivileged, socially devalued citizens. It is interesting how this new-found self-worth experienced by this African American man finds expression in his identifying himself with the privileged, racial other (“the white mama”). While we cannot ignore the irony of the statement, we can cautiously argue that this program helps this participant feel like a worthy consumer of quality care (something that the more socioeconomically privileged have regular access to) rather than a stigmatized welfare recipient.

**Symbolic Motivation: Self-care.** Self-care encompasses those activities like healthy eating, physical exercise, and self-regulation of substance use, emotional self-help exercises and alternative therapy which contributes to better health outcomes. These activities are often self-initiated and may be under the individual’s control and seek to regulate the self with an aim of gaining a certain desirable health outcome. Self-care has been conceptualized as the other end of the spectrum from healthcare provided by trained medical providers (Chambers, Wakley & Blenkinsopp, 2006). The urge to self-care is perceived as an important factor in ensuring desirable health outcome and in chronic conditions like diabetes, hypertension, and long term HIV infection. Self-care in cases of chronic illness is correlated with positive outcomes (Segall & Goldstein, 1989) and is a necessary adjunct to care accessed through the professionals. Chronic diseases need life style modifications and regular adherence to medical advice. Self-care for chronic diseases can be viewed as adopting the medical advice and adapting them to one’s needs and daily routine.



The participants in the study described the urge for self-care. They identified self-care as an important way to ensure their longevity.

It was devastating and really to this day it still is when I see certain commercials or people talk about it in the street it makes me feel fucked up in a sense, you know but then at the same time, I be like everything happens for a reason, that's how I look at it. I do not let it get me down, I do not let it, you know, get me depressed where I feel awful, my life is over because, you know, because being now with all the information they got on it now, you know, how it was back then, then they did not have certain medication and certain things so being now like everything is different now, I feel much more, much better about it. I know I can live longer and healthier, you know depending on how I take care of myself. (Black man, 38 years)

The participant went on to describe how adhering to the medication is now an essential part of his self-care routine:

I wake up, brush my teeth, make myself breakfast and like clockwork, open the bottle of meds. I do not miss a single day. I have done that before. I would not bother. I know now, I know that I can't miss a day. Your levels shoot right back. All this work goes to waste. I tell others too, take care of yourself, like you brush your teeth so that your breath don't stink, take those pills so that you do not rot inside.

Incorporating the act of taking the medicines into one's daily activity is an important way to remember to take them (Rigsby et al.,2000). Comparing taking of the medication with that of brushing teeth to maintain oral hygiene points to how participants have adapted adherence to their quotidian routines. Every single day individuals take care of their bodily needs and maintains physical hygiene with an aim to preserve one's self ("do not rot inside") and be socially presentable ("breadth don't stink"). Self-care thus comprises of these small, routine activities which one may carry on without intense deliberation on a day to day basis.

The VLS intervention and the financial incentives in particular, have influenced many a participant's urge to self-care. A 45-year-old, African American woman describes how she now feels the need to take care of herself more than she did in the past:

I must take the meds, I have to do it better now. I would forget before, but now umm mmm. I can't do that anymore. I need to be on point, my doctor is on point my case manager is on point. I need to be on point. I work hard and try to support myself and stay healthy. I need to take care of myself, you know, if I do not do that I do not have good CD4, I am not undetectable and I do not get my card. Now we can't let that happen (laughs). Now do not get me wrong, I would take my medicines anyway, but now you know it is like everyone will get upset if I do not take my medicines. It is my incentive to take the medicines.

The perception of increased self-worth, as described in the previous section, prompted some of the participants to take greater care of themselves through acts such as routine adherence. The incentive directly stimulates this self-care and adherence behavior by rewarding such behavior at regular intervals.

It is good incentive to know that your health is worth something, you get rewarded for doing a good job with your health. It is like getting the employee of the month, get rewarded for doing a good job with your health. (Mixed man, 47 years)

The money is a reward for a "job well done" and inspires one to engage more broadly with healthy living. A 60-year-old African American woman claimed:

The undetectables program is great because it gets you talking about your health, taking your medicines, eating properly, resting, and taking care of your health. Besides it gives you 100 dollars every four months. I like it because I am undetectable, because I got to do everything in my power to remain undetectable.

She identified taking care of her health as an empowering activity, something that may in itself lead to increased sense of self-worth. For her the incentive is an encouragement

but not a necessary pre-condition for adherence. She says, “Gift card is nice, but my health is more important than a gift card.” This participant reflects a pattern where one acknowledges the role of the financial incentives in motivating better adherence behavior, while at the same time claim that the incentive is not the only reason they stay adherent. An analysis of social desirability underpinning such responses can be useful.

Another participant claims that being a part of the program has prompted him on a path of self-love and self-care, with financial incentives helping him stay the course.

I guess I love myself more now. I want to continue to love myself and look after my health. I check in with myself every day and I tell myself you need to take care. You don't miss a dose. Please take care and love yourself. Who else will? And I have 100 dollars every three months to spend on myself for taking care of me.  
(Black man, 42 years)

For a few participants, self-care and general adherence was directly linked with a desire to maintain a certain kind of “look”. A 35-year-old Black woman confided, “I am vain so I want to look good. You need to take care to look young. I do not want to look all dead and sick.” She further explained that she does not want to prioritize looks over health, but considers good health sometimes makes one look “good and young”. Another participant opined that one's appearance was inextricably linked to one's health status.

We were told that you can't tell if a person has HIV by looking. Yes, when you are young and first catch the virus, you can't tell. But now as we get old, our bodies tell on us. I can look and tell. She has the virus and no she does not take care of herself. I can tell. You end up looking all hollow, your bones show. (Black woman, 42 years)

She concludes that by remaining adherent you can “fool” people into thinking that you do not have the disease.

Look at me, I have been undetectable for so long now. I don't look old like some of my friends. They tell me that they are envious. They say XXX you are gorgeous. Your skin is flawless. I say I want to look this way all the time so I take my pills. My new boyfriend can't believe that I have been sick for so long. I told him, I got you fooled too. Like my friends, he says I am faking it.

In her case the routine of self-care was invested with meanings of beauty and personal pride. Conceiving of health as a state of looking good and feeling good can help patients better relate to the idea. Some patients may find it easier to work towards the personal and subjective goals of looking and feeling better rather than the so called objective biomedical outcomes of blood reports and other bio-clinical parameters.

Continuing the theme of physical appearance and adherence, a third participant pointed out how being undetectable and taking care of one's self was essential for elective gender reassignment surgeries.

For transgender women if you have to get like cosmetic surgery for the breast or bottom surgery, you have to be undetectable. That is for any surgery, you have to be in tiptop shape before they cut you. Like Diabetes it takes us longer to heal.  
(Black transgender woman, 37 years)

Thus, for some participants, looking a particular way whether by maintaining good health or remaining healthy enough to undergo surgery to look a particular way could be attained through routines of self-care. Adherence to HAART was the corner stone for such routines of self-care and self-preservation.

**Symbolic Motivation: Future orientations.** Chronic diseases alter the way people imagine and plan for the future (Bury,1991). For PLWHA (and for the rest of us) the future represents a hazardous state of the unknown. If people believe that they have some control over the events in the future then they are more likely to plan and act on certain measures that ensure a future that agrees with their life goals. In case of chronic diseases, the perceptions of the prognosis of the disease, i.e. how the disease is going to play out in the future, influences how people can plan to take control of their lives. In the case of HIV infection, the knowledge that it can be a condition one can live with helps some people come to terms with its otherwise life altering effects. Planning to adhere to the medications for HIV can form a salient part of how a person plans and prepares for the future.

The participants in the study provided several examples of how staying adherent is now a part of their future planning.

I want to do this for myself. I want to live a long and happy life. I tell people that if I do not do something now how can I live for the next ten, twenty years. I contracted this disease when I was in my teens, now I am in my thirties, I have survived this long, I don't know how, it was God's grace. Now I have these medicines and I can take them every day and get by and get work done. I can feel a change, I can feel that I will live and remain healthy. (Black transgender woman, 37 years)

This participant is clearly hopeful about the future. The fact of her surviving 'this long' instills that sense of hope, she perceives it as a blessing. However, she recognizes the opportunity of good health as promised by the medicines and actively plans for her long and healthy life by remaining adherent. Another participant concurred with her, when she described how she plans her future life and health with the help of these medicines.

I got this when I was 26. I think I was already old then, the kids these days live out their lives in a flash, they are gone before you notice them. I think of the future, I want a job and my own place. I need to live out my dream, I have to live for my dream. I have to keep my health to enjoy the life I want, I can't be dying every day and trying to make by. I need a complete life. I need these meds to work for me. (Hispanic woman, 43 years)

This participant associates good adherence behavior with her desired long life and thinks that she can work at her job and generally make a success of her life if she stays on the path of adherence. She also notes how she does not desire merely to survive ('trying to make by') but thrive on her goals and dreams. Adherence thus becomes a part of that desire to thrive and can also be perceived as the essential gateway towards that complete and healthy future. We have mentioned how adherence has become the gateway, for some, to greater self-care and general healthy living. Here we propose that a plan for the future and imagining adherence as an essential gateway to that future can influence participants' involvement and motivation in maintaining their health.

For some participants, being a part of their family's future was a great motivation to remain adherent. Women especially described how they expect that by taking the medicines and staying healthy they can ensure a better future for their children.

I want to see my grandchildren, so you know that will take a long time (laughs). I take the medicines every day, eat right and plan my life. I think I should be around a long time to see them grow. My daughter wants to go to college. I want to be there for her. I want this to be a happy life for us and see her successful. (African American woman, 38 years)

A-75-year-old, African American man shared how he was motivated to stay adherent by his desire to continue to be the grandfather that his young grandchildren can come to for affection and advice.

My son lives in Philadelphia, he has two boys. They come down and visit me, I go there once a month, sometimes twice. The grandchildren love me. I take them out, you know that place by the river and then they want ice-cream and go to the movies. I love movies, love animation. I watch Family Guy, they cannot watch it (laughs). I watch the Tarzan movie with them. They love me, they tell me their secrets (laughs) something they can't tell their Mama. They ask me what can I do Granddad if I get into trouble. I am an old man so I can help them, have fun with them and teach them from my experience. I have to stay alive for that, if granddad is gone who will take them to the movies? They also ask me you taking the medicines, you taking care Sir? I have to, you know what I mean, I want to see them become men and have children.

Another older Latina woman when asked how she remembers to take her medications everyday said:

While I am taking the meds I imagine my grandchild's face, I am fifty seven and have eleven grandchildren. I imagine them growing up. Yes, I want to be healthy, I want to be there. It is a gift from God- my life, all that has happened to me, now I have to do my part. (Latina woman, 57 years)

While wishing to enjoy of one's own future and that of the loved ones' by imagining a healthy and long life sustained by rituals of self-care can promote adherence, the fear of a ravaged and miserable future-self prompted some participants to focus on self-care. Almost all participants had known a person who had died of HIV/AIDS or have suffered severe ill health and disability due to the infection. Observing, from close quarters, what an unmanaged disease could do to a person provided a cautionary tale for some of the participants. In their turn, they resolved to be adherent and take good care of themselves in order to escape similarly painful future states.

I have seen how my friend died. He stopped taking his meds and never stopped drinking and he dies a slow and miserable death. I see that and get worried. I can't

be like that, umm no. I love myself too much to see that happen to me. I wake up and take my meds and start the day. (Black man, 36 years)

Similarly, another woman describes how she is afraid to look and feel like those who are dying from the disease. She is horrified at the thought of the decay and decrepitude brought in by unmanaged HIV infection and she resolves to eschew that future by remaining adherent and healthy.

I see these people walking around (those who have been non adherent), they are rotting from inside, like a fruit that has been out for too long, sorry I am vain but I do not want to look like that. I do not want to end up a walking zombie, a rotten fruit with dry skin over my bones. I must start now not to get that way ever. (Black, transgender woman, 37 years)

The way a participant saw the future influenced what they felt they could or should do in the present. In case of fatalism, individuals believe that the future is a pre-determined inevitable which is unaltered by any amount of present individual will or action. Such a belief in PLWHA, can lead in some, to complete hopelessness and make them willfully ignore advice surrounding HIV medication and other health promoting guidelines.

I thought I was going to die, so I did not care about meds, doctor visits, reports. I was seeing everyone around me die. In one week, I received news that three of my friends in Detroit had died. I told myself, it is my turn next. They had done nothing to deserve this, I have done nothing to bring this on me. Sometimes you accept it as God's will. I felt I should just have fun. I went out and got high and I was a mess. I did not care where the next one was coming from, I could not get infected again. My mother called up and cried, she asked me to stop drinking and I was like I want to die happy and drunk, not sad and clean (laughs). (Black woman, 50 years)

Hopelessness about the long-term future can cause people to lose the will to live and subsequently they give up on any actions (like adherence and other health advice) that



may influence future health. Fatalism and the attendant hopelessness can result in reduced self-efficacy in trying to adhere to medications and other desirable health promoting behaviors in the belief that they are ultimately ineffective in halting the disease and delaying death. Hence, while imagining and planning for futures can have motivate people to adhere, a fatalistic outlook with an presumed unmanageable future can encourage unhealthy practices which lead to instantaneous gratification like uncontrolled, hazardous substance use as described in the earlier quote.

Breaking this link of fatalism is a challenge for care counselors and service providers, making patients claim agency in their future and hence present lives is an essential first step towards aligning the goals of the patient with that of the provider towards sustained adherence. When the future is perceived as a site of hope and promise, individuals can adopt more positive and pro-active attitudes towards the things that they can do now, in the present moment such as adhere to medication regimes.

Now these medicines make you live long, I have messed up my life before, but now I want to live a happy life. If I do not take the meds I will die, I need the meds to keep me alive and I need to be alive to do all the things that I have planned for myself. (Mixed man, 47 years)

Financial incentives can be imagined as one of the ways to link up present action to future goals. The literature on rewards and incentives claim that contrary to claims of the rational choice theory, individuals often act in ways that are ultimately harmful for their gains or well-being. Moreover, humans have a bias for selecting short term rewards, or immediate gratification over distant, long term benefits. Providing a short-

term reward like a financial incentive for a behavior which has a long-term salutatory effect may be a way to align the need of immediate gratification with long term goals. Participants in this study mentioned how the money helps them out both in the short term and keeps them on track for a healthy future.

The money comes in handy, you know what I mean. 180 dollars every two weeks is tight (referring to welfare benefits). I work towards getting that gift card, yes 'cause the 100 bucks is sweet but I am also taking the meds and making sure I live long and happy. It is a win-win, why change a thing. (African American woman, 60 years)

A 45-year-old white woman observes how for some people she knows in the program the money is helping them do the right thing for the future.

I do it for myself, for keeping healthy. I know of some who do it for the money, I am not sure if they would have done it otherwise. They want the card and hence they get to know their viral loads and stay on their meds. But I see how their health is much better, they say I want the money but I see them getting better and eating more, staying on point and now they will be around for much longer, they will outlive me (laughs) and I am already so healthy.

Instilling such a “future orientation” may be one of the most important goals for a therapeutic relationship that desires sustained adherence. We will discuss the implications of such an approach in greater detail in the next chapter.

**Symbolic Motivation: Community orientation:** Adherence has always been conceptualized as an individual level behavior. However, like most behaviors it is affected by what others think of that behavior, what Theory of planned behavior has called community norms (Ajzen,1991). Community norms are the most difficult to change, and some behavior change scientists have identified these norms to be some of

the strongest factors for bringing about behavior change (Fishbein & Guinan, 1996). In this study, some participants described the community norms as they were prevalent before the program and then they noted how some aspects of those norms have changed.

I have had this virus for twenty years now. Many of my friends have HIV, some have died, some survived. We never used to talk about this before. We were too scared. When we started the medication, we kept it to ourselves. I was like just take it and forget about it. Only once a year my doctor would ask me, are you taking the pills? I used to take them and sometimes I forgot. No one was holding me responsible, asking me about the pills. (Black woman, 50 years)

Another woman described how things were before she started the VLS program:

Too many things to worry about. I was homeless and did not like the SRO room I was allotted, I was focused on getting out. My case worker was helping me with that. I have too much trouble in my life. The medicines would be there in my bag, I used to forget, not because I did not want to take them, but it was not like this when I was being reminded by everyone to take the meds all the time. I did not talk about my disease or my medication with anyone. (African American woman, 56 years)

The program has changed some of the silence around medication. While the participants still described the various stressors in their lives (refer to the later section on “Barriers”), they noted that they had become more mindful of their medical condition and the need to take their medication every day.

The kind of person I am, I take my pills every day. My Doctor is happy with me, she tells me that my blood tests are great. I never have been detectable while on the program. Earlier I may have forgotten a few doses now and then. I was not sure if that mattered too much, but my levels would shoot up. I did not want to be bothered. I wanted to look for work and be on my own. My health was never very bad, but now I know if I do not take care and take my pills every day I can become very sick. I have seen people go like that. I now tell everyone please take your pills, you want to live, right? My case worker, god bless her, she is wonderful and she is always on my case (laughs) tells me XXXX you are taking your pills alright? Please remain healthy. If I do not take care of my body how will I work? The gift

card (referring to the incentive) helps me along, I have it in my wallet as a constant reminder. I am always aware of my health these days. (Black man, 42 years)

The increased awareness about the importance of adherence among the study participants can be partially linked to the more focused conversations that they are having with the service providers about remaining undetectable. The incentive acts as a nudge in directing behavior in some and further focus the conversation around health and adherence.

Being in an environment where everyone was talking about and taking their pills helped many to model their behavior after their peers. The support and the caring environment coupled with the repeated messages from the provider along with the stimulus of the financial incentive made a few participants adhere to their HIV and other medical regimens. A 62-year-old African American woman, resident at one of the transitional housing programs at Housing works, described her before and after story in the following manner.

When I was in North Carolina, I was depressed. I was not ill, I could go to work and live a normal life. But I knew that I will die soon, I went to the doctor and he gave me meds for the depression. I took them for some time and then stopped. I was sure nothing will help.

Then she describes her experience with Housing works and the VLS program:

When I moved here, I saw everyone like me living here and Miss A was so helpful. I loved it here. Then I got tested and my viral load was 1000 and so she said get on the program and you can earn money. I am now undetectable. I would never want to take the medicines before, I was depressed and lonely. Now I take HIV medicines and my depressions medicines every day. You see everyone around you take their medicines and you feel like taking them. You get rewarded for it at the end.

Social support found within the community and at times within the family and romantic relationships encouraged some people to enroll for the VLS program.

My partner was in this program, and she told me to join. She asked me to contact my case worker and see if I was eligible. We live together, so when we join our incentives we can use that for our expenses. Now we are asking each other, please take the meds, we need to remain undetectable and get that card at the end of the month. We help each other with remembering. I am so happy that my wife got me into this. (Black man, 36 years)

The participant in the above-mentioned quote went on to describe how his wife continues to talk about the program, how she is proud to be a part of the intervention and has taken up the duty of spreading the word about staying adherent in her social and family circles. Although, the financial incentive was cited as an initial motivation to join the program, he recognized how they have gone beyond “just that thing” now that they have been adherent for over six months.

Many participants reported that they were talking about the program with other clients of Housing Works and their friends who were not with Housing Works, with an aim to encourage them to join the VLS-Undetectables program. The incentive aspects featured regularly in such conversations.

I told her, why don't you join the undetectables program. You get the reward, you know, one hundred dollars. You will get good care. It is a win-win situation. I tell people, there is no reason that you should not sign up for this. If you do not get your primary care here (at Housing works) then transfer. (Black woman, 35 years)

Participants took it upon themselves to spread the idea about the program. Some went even as far as to claim a responsibility towards the community with respect to the program. A 67-year -old, African American woman described how she considers herself

lucky to be a part of the Housing Works community. She noted her need to spread awareness about adherence to others who might still be misinformed or lack the support that she has received from Housing Works community.

I am blessed to have friends and family. I am blessed to be a part of this community. I feel I need to give back. I need to tell those who do not know about HIV, I need to spread the word about good health and how happy you can be when you are healthy. I am happy to be a part of Undetectables and now I want to give back. At my age, you start to count your blessings and try to give back. (African American woman, 60 years)

The feeling of being a part of a caring community and feeling responsible for its well-being can become powerful mediators of social change. For marginalized communities, in particular, a community orientation can stimulate an orientation for advocacy among the members which may lead to better collective bargaining for their rights (Ghose, Swendeman, George, & Chowdhury, 2008). Conceptualizing health and adherence as outcomes and responsibilities of a community rather than that of individual choices has the potential to bring forth noteworthy and sustainable change in the public health outcomes.

One 62-year-old Black woman underscored how her personal experience with the program was translating to something beyond herself.

I love myself, I take care of myself. I get that reward and keep it in my bag, I feel very proud that I have done my bit to help me be healthy and get that reward in the process. I feel we all need to do that, become healthy and stay adherent. I mean not just take your own medicines but ask others to do it. I want to be a part of the team, I want to tell people that you are worth the care, you deserve the reward.

We have described how the incentives were signaling self-worth in some participants and how that translated into greater impetus to self-care in the earlier sections. Here we

see how that phenomenon is spilling over, or translating to, a sense of communal worth. A notion of self-worth and ethic of self-care is being extended to peers and we notice an urge to forge communal bonds and encourage a communal way of achieving better health outcomes.

Similarly, the future orientation as discussed earlier had a community level analogue. Some participants felt emboldened not only to imagine the status of their own future selves, but also imagined a healthy, morbidity free future for the community of PLWHA and others. The intervention with its impressive aims to improve adherence in an effort to “End AIDS” found resonance in the thoughts of a 65-year-old African American Man, who is heavily involved in advocacy, opined:

We can't stop now. We are so near to the End of AIDS movement. There is enough money. We can go on and end this epidemic, Housing Works can't stop now.

Now that we have explored the symbolic value of the incentive and how it motivates adherence, in the next section we look at the material benefits provided by the incentive and how it motivates adherence.

**Motivation through Material benefits.** While discussing incentives, most research focuses on the motivation to gain the incentives and its effect on behavior in psychological terms. While organizational and corporate psychology research underscores the value of size of the reward and the way it is dispensed (token rewards, cash, salary bonuses, reduction in premiums, (Deci, Koestner & Ryan, 1999; Jenkins, Mitra, Gupta, & Shaw, 1998) no study till date on financial incentives in the clinical setting has discussed the material benefits provided by the incentive or how the

incentive is used by the participant. The present study uncovered the ways in which incentives were used and the results emphasize the importance of the material benefits of the cash incentive as an important element in promoting adherence and other healthy behavior. In the previous section, we discussed the symbolic and psycho-social meanings attached to the incentive, here we explore the actual material implications of the cash reward on the lives and behaviors of the study participants.

*The amount of money received.* Most of the study population lived on fixed income and were heavily dependent on welfare benefits for their daily living expenses. Given this situation, most of the participants deeply appreciated what they could do with the quarterly 100-dollar card. One woman echoed the thoughts of several others' when she said, "I try to make it last, you know, it is like having money in the bank. You can buy things." On being asked what he thought of the actual amount, a hundred dollar per quarter, a 65-year-old Hispanic man said:

It is substantial. It is good. Of course, I would like more, but 100 dollars every three months in great. It helps you to plan for things. It is not like a lunch coupon for 20 bucks that just disappears, but enough money that can get you things that you need (Mixed man, 47 years)

Another participant, a 45-year-old White woman described the cash in hand as "cool little extra, I am very happy to have it." It is useful to remember that the incentive amount of 100 dollars per quarter or 400 dollars per year was decided with the aim for the reward to be substantial, yet within the maximum amount transferable without incurring extra tax liabilities for the recipients.



*What is done with the money?* When asked how exactly the participants used the money, they came up with a range of expenses that they used the money for. Some participants reported how the extra money was used for food.

If you have an empty fridge then I get worried. I get some milk and bread when I get the money. I keep the money for emergency, if I run out of cash and have nothing to eat I reach out for it. (African American woman, 60 years)

*Healthier diets.* Specifically, some participants outlined how they used the money to obtain healthy food.

My bills, sometimes they get overwhelming and I am on a fixed income. I try to eat healthy but healthy food is expensive. You cannot live on junk food with this virus. The money helps with that. I try to save it up for healthy stuff from Trader Joe's, it is not possible for me to get them otherwise. (Mixed man, 47 years)

He went on to further explain his use of the extra money to budget for a better diet:

I am in a group where we discuss how food helps your body to fight the disease. You need to take your medicines, but you also need sleep and good food. I have been very careful with my food. I use that extra money to buy fresh stuff, I take the bus to get the stuff, you don't get good stuff at the corner store. The bus costs money and fresh food costs money so the card comes in handy.

Another 50-year-old African American woman mentioned how it was difficult for her to sustain her healthy diet and how the incentive amount helped her with food.

Since I have my apartment I try to cook fresh food, but 190 dollars not get you a lot. I try to get coupons and my sister comes along to help me save. She drives me to the stores. I plan ahead so that I do not run out of food. The money is good. I save it and go to Walmart and get chicken and frozen vegetables, sometimes that's cheaper.

Access to healthy food continues to be a problem among the poor in the US (Walker, Keane & Burke, 2010). For PLWHA healthy diet can complement regular adherence to HAART leading to positive health outcomes. In this context, our participants reveal

how intermittently (although inadequately) a financial incentive can help them obtain food of their choice. Financial incentives can motivate some participants to obtain better health outcomes by medical adherence and help them, in a limited way, to access healthier diets.

*Utilities and household expenses.* A few of the participants reported how they used the money from the incentive to pay bills and purchase necessary items for their household.

I buy clothes, sometimes I buy stuff that I need around the house. I got a phone, my phone broke so I got a phone with it. I paid my phone bill the next month. I have used the money for paying for data, I use my phone to do face book and youtube so I like to have data. (Latino man, 55years)

The incentive was used by a 65-year-old African American woman to defray the cost of utilities and sometimes help out friend and family in need.

The money comes in very handy, you know what I mean. One month I had to pay extra for electricity and I had the card, so used some of that. I have used the money to buy new plates. One time my sister wanted a loan, I could help her as I had the money. The money is very useful if you know what I mean.

*Indulgences, self-care, and self-reward.* Then there were others who used the money to purchase items that would otherwise have been unaffordable. They used the money to treat themselves to the occasional nice meals and buy consumer goods that improve the quality of their lives.

I go for shopping, I go like to K –Mart or Target. I let it (the cash incentives) pile up and then I get something big. I got a TV, a blender and a toaster.

Some participants felt that it was nice to be able to treat themselves to items that would otherwise be an indulgence. One woman, in particular, had developed a ritual for

rewarding herself with each incentive payment she received. She thus described her ritual:

What I did, I bought a piece of jewelry with my first gift card something to remember you know like why I do, what I do. With every gift card, I get another charm to put on the bracelet. I feel very proud that I can do that, it is a reminder for me to do good things. (Black woman, 42 years)

During the interview, the participant pulled out the bracelet from her purse, proudly displaying the trinkets while identifying them with the month each ornament was bought. She proudly put it on her wrist in front of me much like decorated soldiers donning their service medals. The symbolic value of the material rewards that she had devised for herself constantly reminds her of the task at hand while positively reinforcing the desirable healthy behavior. The sense of self-worth and the ethic of self-care is reinforced by such rituals of rewarding oneself with the money from the incentive, an amount of money that participants perceive as rightfully earned reward.

***Money for substance use.*** Substance use has been identified as one of the major barriers for continual adherence to HIV medication (Hinkinet al.,2007; Mills et al., 2006). Many participants in this study attributed their lack of adherence in the past to substance use habits. Specifically, a 54-year-old African American woman reported that there were times in her life that she sold her prescription HIV medication to obtain “drugs from the street”.

I was undetectable before, then I became detectable because I stopped taking my medication. I was selling it. The reason I was selling my medication was I was short on cash and did not want to go out and prostitute myself, you know what I mean. I sold the meds.

She further adds,

I was using cocaine and needed the money for it. I was not taking the medication anyway, I thought I may make some money with the meds on the street and buy drugs. The money was very little, but I did not care. Any cash was good.

She goes on to describe her conflict with taking the medication and need to obtain the substances she was addicted to: “I wanted to take them, but my need for money was stronger.” Echoing her sentiments about the competing needs of staying adherent and getting high, another Black woman (55 years old) describes how she thinks some of her friends prioritize their substance use over medical adherence.

They are addicted to it. They need their fix and even when they know that my medication is what keeping me alive, I still want my drugs. I tell them take your meds or you will be sick. They are like we want to take our medication but in that moment let me sell them to get money for crack. That’s how it works.

With the establishment of financial incentives, the need for trading the HIV medication for cash was circumvented. The participant (African American woman, 55 years) who described her previous experience of selling drugs described the post intervention situation:

You get 50 may be 20 on the streets. Yes, they still approach me on the streets for the meds. I do not need that money any more. Pharmacies will buy them, people on streets buy them and sell them to other countries.

Participants further pointed out that now to get some money they needed to take the medication and that changed their urge to sell the medication for money.

Now I know I need to be undetectable to get the money, I take my medication every day and that helps me. I still use sometimes, but not the way I used to. I am healthy and I feel good. I do not have to sell my medication anymore. (White man, 57 years)

It is useful to remember that Housing Works, the service provider implementing the financial incentive intervention, utilizes a harm reduction approach and does not require their clients to be addiction free to access services, but supports their de-addiction process. In such a service environment, providing the clients with financial incentives and not restricting what they can or cannot do with the money, respects their agency. It can be interpreted as a refusal to turn clients (who are poor and many have a history of substance use) into docile, compliant subjects who are forced into behaving in a particular prescribed way by their providers. The participants respond to such an empowering approach and appreciate both the material value of the money and its symbolic import (see earlier section on motivation and symbolic significance). One participant sums up the situation neatly when she says:

That's another thing that the program has put an end to. Even if I am not smoking or doing drugs, sometimes I could use that extra money. But knowing that my pills are here and I have to take them to be healthy and get the card makes me want to do it. (Black transgender woman, 60 years)

The issue of concomitant substance use and adherence to HIV care is complex and needs multilevel interventions. However, as shown in the examples presented above, the financial incentive can in certain cases provide material benefits that obviate the need to sell medication on the streets to obtain money for substance use. The logical next question is whether the money so provided enables participants to obtain substances. When we asked this, almost all our participants agreed that it is a possibility. However, none of the participants reported using the money for substances or know of people in the program who were doing so at the time of the interview. They pointed out that getting the incentive as a card and not in cash makes it difficult to use it to buy

substances off the streets. Moreover, they stressed on the process of a reorientation with regards to self-care and self-worth, as promoted by the financial incentive and the larger intervention, as being deterrents to continued substance use. Adherence to medication as promoted in the intervention was a gateway to the larger goal of remaining healthy and taking care of oneself.

In the next two sections, the barriers and promoters for adherence as experienced by our study participants are discussed. We point to how the incentive program in particular and the intervention in general influenced (or failed to influence) each of the factors.

## **Barriers**

While reviewing the literature, we had noted several barriers to adherence. Here we describe some of the common barriers that our study participants reported.

**Forgetfulness.** One of the most common reasons cited by participants for not taking the pills is that they forget to take them. The urgencies of life made many forget the box of pills. Such forgetfulness may signal that the pills were not perceived as one of the most important parts of the daily routine.

People forget, people just forget. There it is in the box but life is happening too, so you do not remember. People are busy taking care of their needs, they are looking for ways to survive. The pills remain in the box and people just forget about them.  
(Black woman, 55 years)

The incentive program may help some to realign their goals of daily routine in a way that taking the pills become important. Being in the program, taking about adherence

and being reminded of the benefits of adherence (the financial incentive being a part of the immediate benefits) helps some clients to try and actively remember to take the pills. Some people incorporate it with daily routines of meals and some others have successfully made it a part of their morning or bed time rituals.

I take them at bedtime every day now. I keep it by the bed. I am more focused now in taking the medicines every single day. I attend the programs and becoming Undetectable is what I want for myself. Every three months I am reminded that I have been taking my medicines every day. It is difficult to forget now. (White woman, 45 years)

A few others would forget to take the pills even when they acknowledged the importance of taking the pills regularly.

I know these pills are keeping me alive. I want to take them every day, like clockwork. But my mind is shot, I forget, and when I get to bed at night I remember. Sometimes I remember a whole day later. I used to feel so bad. (Black woman, 62 years)

The medical provider has since then discussed strategies around missed doses with her and she keeps a phone alarm to remind her of her daily dose.

**Side effects of the medication.** At the time of the interviews, none of the participants complained of any significant side effects that they perceived as a barrier towards remaining adherent. Most of them, however, reported having severe to moderate side effects when they had started their therapy. All the specific complaints on the side effects were adequately handled by their doctors and changes were made in their regimens. A 37-year-old Black Transgender woman related how it was now easier

for her to take the medications since the side effects from the time she started the therapy no longer persist.

**Hopelessness.** Hopelessness was a recurrent theme identified as a reason for individuals failing to stay adherent. They lacked the motivation to take care of themselves through acts such as adherence to medications, since they believed that they were going to die from HIV no matter what they do.

I just was in the give up stage. I felt that I was going to die anyway, so I just did not want to take it. I was in a very low phase and I did not care much about anything. (African American woman, 45 years)

While the incentive program alone could not possibly have prompted them to adopt a more hopeful future, it may have helped in aligning short term behaviors with long term hopes for the future (see above section on “symbolic motivation: future orientations”).

**Fear of disclosure and consequent abandonment.** One participant narrated how she started missing multiple doses of her HAART medication.

But I was not taking my pill. It was something stupid, a boyfriend. I did not want to pop it in front of him. After 2 or 3 days, I forgot where I stashed my pills and I kept missing the meds. Yes, and then I went down, I have always been 1000 or better (referring to CD4 Cell count) but then I went down. (Black transgender woman, 37 years)

She was unable to discuss her HIV status with her boyfriend. The fear of abandonment made her hide her status and made it difficult for her to openly take the medications.

During the times when the boyfriend spent the entire day with her she would have to



forgo the medications. She goes on to explain how her fears of abandonment led her to further neglect her adherence.

It is not an easy thing to tell anyone, you find someone who wants to be with you and you want him to stay by hook or by crook. You feel like no one is going to accept you and you settle for this loser and then when it all begins, and you stop taking care of yourself and hide your medications. (Black transgender Woman , 37 years)

After a health scare with rapidly plummeting CD4 count, she reassessed her life goals. Her boyfriend guessed that something was wrong and finally she disclosed her status. She finally broke up with the man and at the time of the interview claimed to “have been foolish enough to kill myself to keep a man, never again.” This example perhaps ends in a way that some may describe as positive (at least for the participant’s HIV related health ) but signals to the continuing problems of stigma around HIV and difficulties in disclosure. Fear of disclosure of HIV status has been reported by other researchers as being one of the significant barriers to regular adherence (Weiser et al., 2003). However, for our study participant this issue seemed less common. One may speculate that the community orientation and empowered service environment of Housing Works and its continuous advocacy for dignity and rights of PLWHA helps its clients feel less anxious about disclosing their HIV status.

**Grief and personal loss.** Incidents such as the death of a partner, friend or close family members could lead to a disruption of regular routines. While some clients recovered quickly from such incidents and desired to get back their usual routines, others were severely affected by the grief.

My partner had died. That is when everything went downhill. That's when my T cells disappeared; they went down to 47. I went to live with my sister, she helped me out. She took me to the doctors and they changed all my medication. My sister would give me the medicines every day and the nurse would call up at times to check. I slowly got better and then started taking my medicines on my own. (Black woman, 54 years)

Though it is not possible for individual interventions to deal effectively with life events such as that described by this participant, the presence of social support and a service atmosphere which is supportive and responsive to individual needs can go a long way in dealing with these issues. For this participant having a caring sister and being a part of a care system that responded to her needs and prioritized adherence helped her get back to track with her medications.

Apart from these barriers, no other significant barriers were reported by the participants. We did not include substance use as a category here as participants did not report it as a distinct category that they currently perceived as a barrier. We have discussed in the section under material benefits how selling medication for drug money was an issue with some participants and how the intervention was influencing that problem. However, no one identified the use of substances per se as a barrier towards maintaining adherence.

### **Facilitators**

The environment of Housing Works, the policies adopted and the attitudes of their staff members proved to be facilitators of adherence behavior. The VLS

intervention as a whole was a major factor in ensuring better adherence, and financial incentives interacted with the other components of the intervention to positively influence adherence.

**The context of Housing Works.** Housing Works is a HIV focused, housing, healthcare and social welfare service organization based out of New York city. The organization dates to the time of the ACT UP movement in the 1990s that sought to mobilize PLWHA for advocacy for better health care and policy reforms. The organization continues the tradition of advocacy and community mobilization along with quality service provision. The Viral Load Suppression (VLS) program (also called the Undetectables program) was designed to improve adherence to HAART to achieve high levels of viral suppression among its clients. Housing Works is an important partner in the state wide effort to “End AIDS by 2020” in New York, and the VLS intervention is deemed an important component of that endeavor.

Participants in general positively reviewed their experience with Housing Works. Many compared their previous care access experience at other organizations with the special care they currently received at Housing Works.

I was living in San Francisco, and I have never seen anything like this. The people of here are amazing. They welcomed me and have made my transition to New York easy. I appreciate how everyone here is respectful and they get their job done. I appreciate the care they take while dealing with us. (Latino man, 56 years)

The organization provided an environment of care with efficient and empathetic staff. Many clients also volunteer or work for the organization which fosters peer bonding and a sense of a caring community.

This is a place for people like us. You know if you are ready to help yourself, they are there for you. If you do not come on nasty to people then people come forward to help you out. They work with you in trying to solve your issues. I absolutely love it here. (Black man, 42 years)

One participant narrates how the staff have helped her by going beyond her official duties to make services available to her. She feels a deep sense of gratitude and wants to contribute to this community.

Ms A bend the rules to get me in, I am so thankful. I have faced a lot of violence, a lot of hatred for being HIV positive where I lived in North Carolina, but it is wonderful here. I cannot thank God enough for leading me to these people. They never make you feel like shit. They respect you for what you are and then you want to do that for everyone. (African American woman, 62 years)

As a part of their policy, Housing Works has been a champion of Housing first policy, which prioritizes providing stable housing first before any requirements of de addiction is considered. The organization espouses harm reduction approach which does not require clients who are substance users to compulsorily refrain from using, but supports them in their de addiction process. Such an approach provides a sense of dignity and respects the clients' agency. Participants generally approved of such an approach as being respectful and ultimately useful in their journey towards healthy living.

Harm reduction is a good thing. I have been doing drugs for a long time. Doctors and case managers have always been very weary of me. I have never felt discriminated here. I can share my problems with my case manager for I know she is not going to judge me. They do harm reduction here and that has made me feel good about myself. (Black woman, 55 years)

A 62-year-old Black woman expressed a sense of hope, peace, and comfort she experienced by being a part of Housing works. Such an environment helps her to follow

medical advice, plan her future and she views herself as an activist fighting for a common cause.

We are a community of activists here you know. The kind of person I am, I want to give back to these people, they have been wonderful about everything, they got me the apartment have great doctors from here so I can figure out my life. I have had it very hard, so I appreciate all the help I get and I want to become an advocate for other people here. Housing Works has good doctors and case managers. I have nothing to complain. I am very happy with the program. The service is tip top.

Some participants actively advised their friends to transfer to Housing Works given the quality of their service. A 38-year-old Black man moved to New York to get services at Housing Works and he does not regret the decision.

My friends if they ask me, I always telling them to transfer to Housing Works. I moved here from Philadelphia to be at Housing Work. It has such great services. I am very happy with the move. I wish we had such services in Philly. I feel very good about coming here. You see these familiar faces and they ae friendly and helpful and you know many of them as positives like you, it is a great place to come to for your PCP.

The de-stigmatizing context of housing works is an essential facilitator for adherence among its clients. The resources and services along with the context in which it is provided helps clients feel respected, empowered and motivated to adhere to medical advice received from Housing Works. The meaning making process associated with the financial incentives as described earlier can operate in the particular environment made possible by the policies, attitudes and norms of the service and advocacy organization.

**Care Provider-Patient relationship.** The therapeutic relationship has been idealized as a partnership between the provider and the recipient of care (Pearson & Raeke, 2000). Adherence studies have underscored the importance of the provider

patient relationship as an important factor influencing the quality of adherence (Mills et al., 2006). Our study participants report how their relationship with their care providers - doctors, nurses, and social workers - have impacted their adherence practices.

In general, many participants reported being happy with their present care providers. The intervention required all participants to be receiving their primary care from Housing Works. While most participants were already recipients of primary care from Housing Works at the time of inception of the program, some had switched their providers to be able to join the intervention program. From the vantage of being new to the system they compared their previous care receiving experiences to that at Housing Works.

I like her (his current PCP) better than my doctor in Philly. I used to see him only a few times a year, here she keeps me on my toes. I did not have the time to discuss how my meds are treating me, now I talk about them all the time. My doctor, she listens to me and I can be free with her. (Black man, 38 years)

The regular clinical visits and the renewed focus on adherence has helped many participants in making better decisions about their adherence.

In particular, some participants described how the ease of communication with providers have helped them to make deliberate, informed choices about their adherence practices.

We have that kind of relationship. My doctor tells me, 'you have to up it, the tests are not good.' I like that we can talk like this. I can tell her that I am not taking my meds because I am stressed. Then she says, that even though you are stressed you are supposed to take your medication, that is what making you live. (White man, 47 years)

The participant stresses on the fact that unlike in the past, now he feels more comfortable talking to the doctor regarding his issues around adherence. The increased discussion inside and outside the clinic about adherence and the “virtues of being undetectable” have empowered the participant to actively engage in his care decisions.

We have discussed how the intervention has created a perception of increase in the level of care received among some client participants. Many noted the greater availability of nurses and other clinical staff and their willingness to engage in care. While describing his experience with the Directly Observed Therapy (one of the tools in the intervention kit, discussed in the next section), one participant appreciated the ease with which he can access some care giver over weekends now as compared to what he could during earlier times.

I can now meet up the nurse through the weekends to take the medication. It is wonderful to have that, not to wait for the next week to talk about your problem but you can do so right away. It is easier to get hold of a nurse and have them listen to you. (African American man, 55 years)

The case managers have always played an important role in the care coordination and linkage to services for the clients. As a result of the intervention, they were now more likely to have direct conversations about adherence to HIV medicines along with providing other essential care and counseling services. All the participants expressed their satisfaction with their case managers and identified them as major allies in their journey to adherence, health and well-being.

I love Miss E, she is very nice. She always asks me, Mr. M have you taken the medicines? How is everything going? I can trust her to do the best for me. I

absolutely love that I have her as my case manager. I am thankful for all her help. I am happier today and healthier because of what she has done for me over the past year. (African American man, 65 years)

Specifically, with regards to the financial incentive, our participants reported little change in their relationship with their care providers. This is an important finding since some opponents of financial incentives claim that a financial incentive undermines the quality of the therapeutic relationship. Incentives, they claim, can be viewed as bribery from the provider to the patient. Given the unequal power relationship between the two, the patient may feel coerced into following the directions under the sway of authority and financial gain. The trust based relationship of care is impaired and it erodes to one of transactional gains.

The participants in our study did report discussing the attraction of incentives with their care providers. However, it was seen as a reward for their conjoined efforts at securing good adherence and health for the patient.

My doctor tells me, you have to take your medicines every day. Let me know if you have any trouble with any of the pills. I want you to remain undetectable and get all the reward cards. I feel she has my best interests at heart always. I thank all of them every time I get the card, it would not have been possible without them. (Black woman, 62 years)

**The VLS Intervention tool box.** The VLS intervention provided concrete tools/services to the patients to deal with their adherence issues. The tools consisted of Directly Observed Therapy, Adherence Support Groups, and Text message reminder systems. The program was also associated with an effective social marketing initiative



that helped enroll and retain clients. The Financial Incentive was an additional provision that was expected to motivate the clients in the context of the other adherence focused services. Let us see how each of the tools and program components facilitated adherence and interacted with the financial incentive scheme.

***Directly Observed Therapy.*** As per the intervention protocol, patients who had severe challenges with adherence could opt for a Directly Observed Therapy (DOT). Here the patient comes in every day and takes the medication under direct supervision of a nurse. Some may eventually come in once every week to check in with the nurse after the initial daily visits when they feel more confident that they can regularly take their medicines on their own. The participants who had taken part in the DOT arm reported how it had helped them get back into the habit of taking the medication daily.

For the entire year, I came in to take my pills, earlier I would take it when I felt like and miss it often. (Black woman, 50 years)

I would forget, just plain forget, but when I started doing this(DOT) every day, I remember. I started to remember and it helps me remember now, because it is a part of my routine. (Black woman, 42 years)

Participants recognized the demands on their resources of time and money needed to come in everyday for DOT, however they generally acknowledged that the benefits justified the costs.

I had to take the train every day to come in to Cylar House. That was not a problem, it put pressure on my pocket but it was totally worth it. (Black, Transgender woman, 62 years)

Following daily DOT regimens, many participants whose adherence stabilized over weeks or months, were set up with pill boxes. Participants could use pill boxes received through the intervention (some had their own) irrespective of any DOT services. Pill boxes came in handy for many of the participants especially when they were travelling and staying away from their usual residences.

Here is my pill box, I have taken all the medication you know. This makes a difference. I do not know what kind of difference but a very important difference.  
(Black woman ,50 years)

***Adherence Support Group.*** Adherence support groups were made available through the VLS program. They used a combination of CBT and motivational interviewing techniques with an aim to empower the participants and eventually hand over the running of groups to the peers. Participants who were initially non-adherent or have had relapses were encouraged to attend these groups. However, some of the most regularly adherent participants also attended the groups and found the experience useful. A Mixed-race man of 54 years exclaimed, “I like those. We talk about being healthy, eating right and taking the medicines.”

The adherence groups dealt with issues of holistic good health in PLWHA while underscoring the importance adherence to HIV medications. The peer led approach was enthusiastically commended and helped secure the continued interest of the participants/facilitators.

They let me facilitate one of them, I really liked that. I felt I was doing something very useful. I look forward to doing more of those. (African American woman, 54 years)

Participating in these groups made some of the clients feel empowered with regards to their disease and has inspired others to become advocates for good adherence behavior, holistic health practices and well-being of PWLHA in their service community.

Well, my topic was becoming, staying, and remaining undetectable. I shared my story and helped people become that way. (Black woman, 50 years)

**Reminders.** Two other of these intervention tools that were related to those discussed above are the RINGO text message reminders and the “buddy system”. The text message reminder was a system of DOT implemented through text message reminders, where the participant receives a daily or weekly message reminding her to take her medication. A 36-year-old Black man mentioned, “They send me a message every day, that helps.” Another participant said:

I have not used the service, I remember on my own, but others have and I recommend it to those who find it difficult. They say it really helps them (Black woman, 50 years)

Forgetting to take the medication was one of the most commonly cited reasons for uneven adherence, and these reminders helped in those cases. Participants themselves devised alarm reminders on their phones to help them remember the time of taking the daily pills. A 43-year-old Hispanic woman said, “I set an alarm and then the message comes in, so I remember to take the pill.”

Another source of reminders for the clients was from each other. In general, we have noted how the increased discussion about adherence created an atmosphere where clients, in contact with the system and each other, were now more likely to talk about and hence remember to take their HIV medications. Furthermore, some clients formed a buddy system through their adherence support groups where they have a peer in the group – a buddy- and check in on each other via calls or text messages.

I have a friend ring me up. I ring her up too. We check on each other -have you taken the pills? please take them. That's like having a person care for you. (African American woman, 56 years)

Family and friends who are not a part of the service community also check in with participants and motivate and remind them to take their medication.

My daughters ring me up every day and ask 'have you taken the medicines?' they love their father, I do not know why. My buddy also calls and checks in with me. (African American man, 64 years)

Thus, the buddy system augments the existing social support, and enhances the chances of better adherence among the participants.

***Social marketing of the program.*** The VLS program roll out was accompanied by a massive social marketing scheme. The complete description and analysis of the effort is beyond the scope of the present study, however, here I briefly outline the major effect it had on the uptake of the program and adherence among participants.

Housing Works started a social marketing campaign around the VLS project under the name of the “Undetectables”. They had flyers and posters advertising the intervention displayed in all the clinics and other housing works facilities across New

York city. Additionally, they published periodic brochure designed as graphic novels which documented the stories of the participants as they narrated their experience with HIV medication in a bid to become virally undetectable. The women and men were portrayed as super heroes with special powers that has led to their special undetectable status. The idea was to promote interest in adherence and healthy behavior by reframing them as super powers that makes one a super hero-The Undetectable. Such a social marketing approach stimulated a lot of interest in some of our participants and they enthusiastically recounted their encounter with super heroic fame.

I love them (the super hero comics). I want to be in them, my wife has been featured. Yes, she was very proud. She was in the program (VLS) longer than me, she got me into the program. She asked me to join. She was so excited the day she got the book, she was in it. It is like I have super powers now, I am strong. She is an advocate, she wants to go and talk to people about this. You also get the money (laughs) and I get it too, so we have 200 for the house now. (Black man, 36 years)

The comics become a way for some participants to talk about adherence and their other health issues with their family and friends.

The comics are very cool, she gets them home and gives them to her family, they are proud. When she is sad she reads them. My wife is very fond of the comics. She likes to draw, so she loves art, the books are her thing. I joined Undetectables after she got me the books. (Black man, 36 years)

Identifying with the super hero characters activated some of the meaning making processes around self-worth and self-care in a way similar to that of the incentive as described earlier. A 37-year-old, Black transgender woman described the attraction of the books in the following manner:

I like to look good, trans women are very vain, they love their looks. I take care of my skin and diet and my meds. It is like superwoman, we have the super women in comic books at Housing Works. I think Trans women want to be that, super women, we are big (laughs) and powerful, we want to beat this thing and use our powers to get what we want.

Others appreciated the effort as an effective means to communicate with a younger population. The following quote illustrates how an older adult (75-year-old, African American man) used the comics to talk about himself with his grandchildren.

I am an old man, I do not read comics, but my grandchildren they love the comics. You know Family Guy, yes. They saw the comic books and they liked it. I think young people like the comic books. My son read that and saw the poster and he asked me about this program. My grand -kids saw the comics. They asked me are you like batman now? (laughs) I think they are good.

Some saw the comics as an excellent way to reach out to a more diverse population with regards to age and literacy levels. A 65-year-old, African American man suggested wider and more aggressive outreach using the comic books.

Why can we not have the comics all over the city? Not just at Housing Works, but every at doctor's and clinics. Young kids can pick it up and come get tested. You asked what Housing Works can do for younger kids, they can circulate these magazines. 15 -16-year-old kids can read this and get some idea. They can't ask their parents and they do not know everything about sex from school, so they can read these and know. I think it is a good effort but Housing works should send them to all hospitals and clinics.

The facilitators described above created the right environment for effective uptake and engagement with the financial incentive program. In the next chapter, we will see what implications this has for the future of financial incentive in theory, policy and practice.

**Conclusion**

The theory presented in this chapter explains the way financial incentives work for the specific community setting of Housing Work clients who are living with HIV. It brings into focus the dynamics of incentives, its constituent processes of symbolic and material effects on motivation. The context in which such a dynamic works is also explored in some detail. In the next chapter, the salient finding will be discussed in an attempt to place the study in the context of other theories and suggest possible future implications of this study.

## **Chapter 5: Discussion**

### **Introduction**

Economists and other social scientists have tried to understand how incentives work to motivate individuals to carry out behaviors in an array of settings, such as schools, work places, consumer markets and health related situations (Giles, Robalino, McColl, Sniehotta & Adams, 2014; Solomon et al., 2014; Ryan & Deci, 2000; Jenkins, Mitra, Gupta & Shaw, 1998). This study in the main sheds light on the process of motivation for adherence in the context of financial incentives. The results have been organized in two main domains: motivation derived from symbolic interpretations of the incentive and motivation provided through the material benefits of the incentive. Moreover, the context of barriers and facilitators to motivation as found in our sample have been discussed. In the following pages, implications of each of the salient findings, to better elucidate the dynamics of motivation as activated by financial incentives in a clinical setting, are discussed. It is followed by a discussion of the implications of the results specifically with regards to theory development, practice directives and policy recommendations. We conclude with a review of the limitations of the study and avenues for future research.

### **Decoding Motivation**

Motivation research can be traced back to the experiments of Skinner whose work on operant conditioning laid the basis for behaviorism movement in post war psychology (Skinner, 1963). The idea was that by reinforcing certain behavior with



rewards, one can strengthen or reinforce that behavior (Wolf, Risley & Mees, 1963). Scholars have since questioned the applicability of Skinnerian models, which was developed mostly from animal testing, to humans in complex social settings (Staub, 2016). Later work on intrinsic motivation (see Chapter 2 for detailed discussion) has maintained that external rewards can crowd out intrinsic motivation resulting in less diligent pursuit of behavior that is reward contingent. Economists have disagreed with this view claiming that external rewards may indeed be the rational choice for individuals which work by increasing higher marginal gains on performance (Fama & Jensen, 1983). Financial incentives for health behaviors provide an immediate reward for an action which is construed to be beneficial in the long term. Humans have a present bias which means that they seek more immediate rewards in the present than wait for supposed long term gains (Kamenica, 2012). The study participants recognized this phenomenon and appreciated both the immediate gain of the reward as well as the long-term benefit of regular adherence. An alternate theoretical understanding of this phenomenon can be gained by looking at ideas of delayed versus immediate self-gratification. Mischel's experiments in the 1960s which have been dubbed as "the marshmallow experiments" have been influential in the discourse of delayed self-gratification (Mischel, Ebbesen, & Raskoff Zeiss, 1972). In these experiments, children were offered an immediate but relatively small reward (such as one marshmallow) or if they waited for fifteen minutes then a larger reward (two marshmallows or something more substantial). The experimenter left the room after explaining the initial condition and the child was left alone in the room with the first marshmallow. The time each child

waited till they ate the first mallow was noted. Tracking the children over the next several years, researchers found that those who managed to delay their gratification and opt for the delayed larger reward had better life outcomes in terms of SAT scores, educational outcomes, and body mass index among other life outcome measures (Ayduk et al., 2000; Mischel, Shoda, & Rodriguez, 1989; Schlam, Wilson, Shoda, Mischel, & Ayduk, 2013; Shoda, Mischel, & Peake, 1990). In 2012, the experiments were recreated but with one significant difference (Kidd, Palmeri & Aslin, 2013). One group of children was given a broken promise before the marshmallow experiment (the unreliable test group) and the other was given a fulfilled promise before the experiment (the reliable test group). The children in the reliable test group showed longer waiting times for the second marshmallow to appear than those in the unreliable test group. These results have raised questions about how delayed gratification may not be a function of individual self-control but influenced by the environment. In other words, for some delaying gratification may not be a rational choice given the unreliability in their environment of obtaining the rewards in the future (Staub, 2016).

We propose that financial incentives for marginalized, poor people with chronic conditions like HIV, provides a form of immediate gratification. For them, the chaotic insecure environment of welfare benefits, unstable housing and uneven health care creates an incentive to accept immediate benefits rather than laboriously cultivate self-control and modify present behavior to live out a distant, uncertain future. The immediate gratification motivates them to pursue the incentivized behavior which may subsequently be appreciated as a long-term investment in their own health and well-

being. Participants of such an incentive program may gradually begin to imagine futures (some may have already imagined a future as our results show) which they perceive as being less chaotic and amenable to some degree of present control through actions such as adherence which maintains their health and contributes to their longevity.

### **Self-worth**

Low self-worth or self-esteem has been, for a long time, correlated with adverse health outcomes (Mecca, Smelser & Vasoconcellos, 1989). Later research has sought to nuance the understanding of self-esteem and self-worth and its influence on psychosocial outcomes (Crocker & Knight, 2005; Crocker & Wolfe, 2001; Rosenberg, Schooler, Schoenbach & Rosenberg, 1995). However, researchers generally agree that self-worth is influenced by how individuals are perceived by social others. Approval from significant social others usually positively influences the perceived level of self-worth (Crocker & Wolfe, 2001).

The results from this study demonstrate how a service and care based intervention can provide approval and validation of self-worth for certain individuals. First, some participants appreciated the increase in focus and quality of adherence related services. This increase in services and concentration of care was perceived as a novelty and a marker for the regard the care providers held for the well-being of their clients. Second, the provision of the financial incentive in itself sent home a message that the providers were not only committed to provide services but also actively approve and reward of the client's effort to engage in them. Both- these perceptions led some

clients to appreciate their own self-worth and boosted their desire to engage with the providers as deserving consumers of care.

While the recent study by Greene et al., (2017) reported how participants in an incentive program perceived the incentive as a sign that someone really cared for them, the significance of such a process uncovered by the present study assumes special significance given that the participants were welfare recipients and relied on state sponsored HIV care services. In the United States under the means tested welfare system, welfare recipients are perceived as helpless dependents at best and as lazy free riders at worst (Blau & Abramovitz, 2010). In such a context, the intervention with its host of services and the financial incentive was deemed as a special effort to help clients gain better standards of adherence and through it, good health and well-being. Without stigmatizing them, the intervention sent out a message that one was worthy of good health care services and one deserves to be rewarded in an immediate and concrete manner (through the incentives) for actively seeking the services and successfully engaging in the shared goals of better health. The intervention, thus, supplied an example of how provision of services can foster a sense of self among the recipients that can go beyond the stigmatized dependent and articulate one of a rights seeking citizen, who can demand better care and refuse to be devalued and written off as liabilities of the state.

**Self-care**

Related intimately to the perception of self-worth was the urge to self-care. Though it is not directly derivable from the results of this present study, there is an intuitive appeal in the idea that all things being equal, a greater sense of self-worth can result in higher levels of self-care. As indicated by the results, this urge to self-care formed the main impetus to greater adherence behavior in many of the participants.

Self-care has been theorized most famously by Dorothea Orem (1991) who considered it as a necessary idea to conceptualize nursing care goals and practices. She defined self-care as activities undertaken by individuals on their own to maintain life, health and well-being (Orem, 1991). It follows from her concepts that while every patient needs to engage in self-care, there may be deficits between the ability for self-care and the needs for self-care. Nursing interventions were understood to meet this need. Building on Orem's theories and adapting them for chronic diseases, Reigel, Jaarsma and Strömberg (2012) suggest that self-care consists of maintenance, monitoring and management activities. Adherence to best care practices fall under self-care maintenance. Health care interventions for chronic disease patients must focus on adherence to maximize the therapeutic effects of treatment and ensure long term well-being.

The results show that many participants identify adherence as being a necessary part of their self-care routine. Moreover, many participants claim to engage in wider activities, such as maintaining personal hygiene, eating healthy and exercising to complement their HAART adherence practices. The broader VLS intervention provides

them with tools for better self-care (such as support groups which discuss how to live healthy with HIV) and the financial incentive provides them with an immediate short term reward to stay the course of adherence. While we cannot claim that the incentives directly stimulate other self-care routines apart from adherence, it has been a common finding that health behaviors occur in clusters (Pronk et al., 2004). Hence, the participants claimed that they engage in greater self-care along with adherence, with the incentive providing a direct motivation for better adherence. Most participants who reported self-care identified the desire to remain healthy, while a few explicitly claimed that self-care was an essential path to ensure they looked good. These different articulations of the goals for self-care can provide useful guidelines for practitioners when they engage patients in counseling for self-care.

Taking a further step in the discussion of self-care, the political and advocacy implications of a self-care ethic are critical issues to keep in mind. Neo liberal ethos promotes self-care as a means to create increasingly efficient and productive human bodies and minds. There has been a marked rise in the cult of physical exercise, yoga, celebrity endorsed healthy diets and self-help psychology books which cater mostly to the middle and upper middle classes. While promoting healthy behaviors in themselves cannot be harmful, self-care regimes as indexed by the phenomenon mentioned above, can be seen as an economy of indulgence in which only the well-off can participate. The radical black, feminist thinker and political activist, Audre Lorde, provides us with a counter narrative when she says, “Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare” (Lorde, 1988). Some consider the

marginal citizen a liability for the state (such as welfare recipients and recipients of Medicare and Medicaid in the US) who can be easily dispensed with. When individuals engage in self-care, according to Lorde, self-care becomes an act of political activism. By perpetuating one's existence (and thriving) through acts of self-care they defy the powers that be, which may as well have them dead if not through overt acts of violence then by systemic negligence and structural deprivation. We argue here that for our participants self-care has a similar political possibility. Given that they were poor, stigmatized welfare recipients and mostly identified with nonwhite races, they are eminently the disposable citizens much reviled by the neo liberal state. As they gain in self-worth and engage defiantly in self-care activities, both of which this study found to be influenced by the intervention and financial incentives, one can argue that they are engaging in grassroots political advocacy on behalf of themselves and similarly marginalized groups within the US polity.

### **Future orientations**

Imagining futures amid the chaotic present-day environments motivated many participants to adhere to their medication regimes. As discussed earlier, the short term financial incentive to act in the present helps individuals align their behaviors for benefits in the future. Furthermore, as discussed in the results, participants thought of both a healthy promising future which they could be a part of, by maintaining adherence, as well as a hazardous, morbid future that they may actively forestall by engaging in adherence and other self-care behaviors.

While some studies on adherence have noted the role of future orientations as a predictor of adherence (Mills et al., 2006; Remien et al., 2003), our study explores the phenomenon with regards to motivation in some detail. Sandberg and Corner (2008) in a meta-analysis of studies employing the Theory of Planned Behavior (TPB) identified Anticipated Regret as a significant and independent predictor for intention in addition to the TBP variables. Regret is defined as “a negative, cognitive-based emotion that is experienced when we realize or imagine that the present situation could have been better had we acted differently” (Sandberg & Corner, 2008). Regret can also be anticipated before an action to avoid an unpleasant future and disagreeable emotions (Simonson, 1992). Hence future adherence studies should further explore the role of anticipated regret and a future orientation to better understand, predict, and modify motivation for adherence behaviors.

### **Community orientation**

The Theory of Planned Behavior identifies norms as an important predictor of intention and behavior (Ajzen, 1991). A desire to conform to social/community norms can become a powerful way to alter behavior (Linnemayr & Rice, 2016; Allcott, 2011). We find that the VLS intervention served to positively modify the community norms about adherence with participant clients and their providers focusing on adherence and its importance in their care plans and goals for well-being. The incentives encourage the uptake of adherence behaviors among the clients and some clients talk about the incentive program to encourage other community members to join the program and stay the course of adherence.



The increased sense of self-worth, the urge to greater self-care and a future orientation was translated from the level of the individual to that of the community. Some participants claimed that they were now more concerned with the health and the future of the community of service recipients at Housing Works and urged each other to engage in self-care and adherence. While such a community orientation must have existed prior to the intervention given the history and the approach of the service provider community at Housing works, we can attribute the focus developed on adherence at a community level largely to the VLS intervention program.

Bandura (2000) identifies collective efficacy as an important vector of human agency.

People's shared beliefs in their collective efficacy influence the types of futures they seek to achieve through collective action, how well they use their resources, how much effort they put into their group endeavor, their staying power when collective efforts fail to produce quick results or meet forcible opposition, and their vulnerability to the discouragement that can beset people taking on tough social problems.

The VLS program resulted in a perceived increase in the collective efficacy to adhere to HAART medications and ultimately to eradicate the AIDS epidemic. Along with the political activism of self-care and seeking better health services as a matter of social and political right, the collective approach towards HIV care harks back to the history of HIV activism and has enormous potential for mobilizing different groups of people in an effort to contain the HIV epidemic and improve the life outcomes of PLWHA.

**Material benefits**

The reasons offered to explain motivation provided by incentives have been largely psychosocial with one only study recording how participants appreciated the financial benefits from incentives (Greene et al., 2017). Our results show that for indigent people with fixed income through welfare benefits, the actual value of the money from the incentive is an important component of motivation. The money was used to obtain better diets, defray personal costs, and also used for otherwise unaffordable luxury items for self-reward.

Previous research has demonstrated the enabling effects of food assistance, in particular, for better adherence in HIV and tuberculosis patients (de Pee, Grede, Mehra & Bloem, 2014). Incentives utilized for food and other needs by poor patients can become useful ways to ensure better outcomes and motivate adherence behaviors in them. The material benefits derived are thus irreducible to exclusive psychosocial understandings of symbolic value and intrinsic motivation parameters.

**Provider patient relationship**

The opponents of financial incentives have raised concerns about how it may erode the trust based relationship of the therapeutic alliance between the patient and the provider and reduce it to mere calculated transactions (Oliver & Brown, 2012; Marteau, Ashcroft & Oliver, 2009). The participants' experiences oppose that view. Many of them described the sense of comradeship with their providers as they jointly made plans for better adherence. The participants reported how their doctors, nurses and case managers

discussed the benefits of the program in general and financial incentives in particular, and motivated them to earn each incentive by diligently attending to their adherence. No participant perceived a sense of coercion via the incentives from their care providers. The providers encouraged them to view the incentive as their rightfully earned reward. The patients thought that the providers themselves took pride when their clients claimed the reward at the end of each quarter and considered it as a triumph of their therapeutic alliance.

These results underscore the importance of the approach of the providers and their acceptance by the clients for the success of financial incentive programs. Even when we acknowledge the power differential between marginalized clients and their providers who act as gatekeepers to services, the value of a partnership approach to the therapeutic relationship cannot be undermined. The clients have no choice but to assume that the providers are competent and have their best interest at heart while administering care. They however, can be further reassured and motivated to adhere to the prescriptions and advice if they are treated with respect and dignity, as agents of their own care rather than passive recipients of the ministrations of providers.

### **Context of Care and Financial Incentives**

The major reason financial incentives seem to work under the VLS intervention scheme, is the way they were provided and the attitudes and policies of the provider organization. The clients were presented with a whole range of adherence focused services (support groups, DOTS, text message reminder systems) which aided them to

get over barriers such as forgetfulness, isolation, apathy and lack of information about medication effects. We propose that the financial incentive can only work in a context where other services are in place that help clients with their medication adherence issues. The financial incentive is an additional source of motivation, but it cannot substitute medical and other social services that help clients with their individual problems in maintaining regular adherence. Neither should we assume that the services and incentives could provide a fool proof and comprehensive solution to all individual barriers such as personal loss and grief, idiosyncratic reactions of HIV medications and other unforeseen life events which disrupt regular adherence goals. Comprehensive care remains the only long term solution to poor health care outcomes.

The context of Housing Works with its focus on harm reduction and grassroots advocacy also formed a major source of support and inspiration for the clients. The incentive program was well received since the clients were not made to feel like stigmatized benefit recipients but deserving candidates for care and the attendant financial incentive. The dignity and autonomy of the clients were respected in the organization which had salutatory effects on the uptake of the program and facilitated the positive, self-validating effects on individual clients. Moreover, the intimate nature of the service provision environment facilitated client motivation and helped them to positively view the financial incentives. Research has shown that incentives work better in smaller clinics (El-Sadr, Branson, & Beauchamp, 2015) rather than larger ones where the care though competent, may be perceived to be impersonal.

**Equity and decommodification**

While we propose that the material benefits of the incentive for poor clients cannot be ignored, the benefits derived cannot be exclusively understood through material terms of utility and increase in purchasing power. The meanings attached to the incentive creates more than transactional values. In a manner, the money provided decommodifies the recipients as they made sense of the incentive and converted it into instruments of self-worth, self-care and self-reward. Decommodification is a term first used by Esping-Anderson (1990) to describe the different welfare state regimes of developed nations. It can be understood as a way for individuals to escape the state of being reduced to labor for sale in market economies. Decommodified subjects become citizens with rights to a basic standard of living. While Esping-Anderson used quantitative data to obtain indices of decommodification, here we employ a qualitative use of the concept. The VLS intervention created an environment where marginalized and socially devalued individuals accessed quality care and they were given direct financial incentives to engage better with that care and follow its prescriptions. In a way such an intervention, when funded with public money, seeks to extend the responsibilities of the Welfare State. The State is not only deemed responsible for providing quality health care but actively spends public money in engaging the client-citizens in that care. The State strives to provide curative measures for the disadvantaged (like it does with affirmative action) to promote equity. Fundamental to this approach is the recognition that those who are disadvantaged by long standing structures of racial, economic, and social inequalities need additional assistance to meet

their needs for health and well-being. In justifying the right of their citizens to access that care and get incentives for accessing that care, the Welfare regime is recognizing their hitherto marginalized citizens as rightful claimants to its resources.

### **Implications for Theory – filling the gap**

This is one of the first studies to qualitatively look at financial incentives for adherence to HAART in people living with HIV/AIDS. The other recently published work by Greene and colleagues (2017) also looked at financial incentives and adherence to HAART, but the present study differs from it by engaging in a deeper analysis of the issue and by employing a constructivist grounded theory framework it developed a situation specific middle range theory for the phenomenon. It offered a more nuanced understanding of the influence of incentives on motivation than previous theories in three major respects.

First, it provides specificity for the clinical situation. Other financial incentive theories have been based largely in education and work place management. It arrives at concepts such as self-worth, self-care, and community and future orientations as ways to explain motivation. These concepts have been studied by behavioral physiologists and medical sociologists, but never in conjunction with medical adherence and incentives.

Second, it brings together both psychosocial theories of symbolic worth as well as materialist explanations, in one theory, to explain adherence behaviors. It explores both individual level phenomenon and links it to broader environmental issues such as

context of service provision, provider patient relationship that influence outcomes. The broader socio- economic factors of gender, race and class have been hinted at during the analysis, but these factors could not be adequately explicated through the present study. The section on limitations and future research further discusses this issue.

Third, the study offers some answers to the debates on financial incentives. It examines the effect of financial incentives on the therapeutic relationships: whether incentives are perceived as bribery or coercion by the participants and how incentives affect the provider patient relationship. Although not directly answering the question, it also offers a way to frame an argument for the social and political desirability for public spending on incentives.

The study inaugurates a new perspective on the research on incentives. It calls into question both the rational transactional model of behavioral economics, as well as the highly psychologized approaches of intrinsic motivation and individual control seen in education research. Research with incentives for patients in the clinical settings thus challenges, synthesizes and posits a different, more nuanced approach towards imagining the effects of incentives on individual's behaviors. Future research strategies to refine and validate the theory presented in this study is discussed later in this chapter.

### **Implications for Practice**

The theory developed from this study helps us understand the dynamics of the process of motivation for adherence in PLWHA. Practitioners caring for people with

HIV can engage with their clients in discussing the specific aspects through which motivation for adherence is conceptualized to work in the specific clinical settings.

Given how self-care emerged as an important aspect of motivation to adhere, doctors, nurses and social workers should focus on the aspects of self-care and explore how patients can adopt self-care routines. Encouraging the patient to imagine adherence as a part of a more general self-care plan can help initiate and maintain adherence and other evidence based care practices. Motivational interview techniques can be used to elicit the goals of self-care routines and help patient work through challenges and barriers. Different patients may have different goals for engaging in self-care (looking good, enjoying good health, living for others, avoiding morbidity and disability) as shown by the results, hence, providers need to elicit and discuss these with their patient-clients. Orem's theory of care in nursing practice claims that nursing care is basically a way to bridge the gap between capacities of self-care and the need for care (Orem, 1991). Especially for chronically manageable diseases like HIV, where most patients do not need intensive everyday medical care from professionals, practitioners can expect better health outcomes from inculcating an ethic of self-care among their clients.

When discussing the goals of self-care, practitioners must also consider the role of future orientation as discussed earlier. Counselors should engage the clients in discussing how they imagine their futures and encourage them to break the link of fatalism to adopt more proactive approaches to the future by adopting adherence and other health behaviors. Such future orientated discussions will necessarily involve more than just health practices and that is where social workers with their diverse skills can



help address the patient's concerns about future contingencies such as housing, financial planning, and geriatric care issues.

The results from this study reemphasize the role of patient centric approach to clinical care. Acknowledging the patient's autonomy and agency will be key factors in obtaining buy in from the patient which will ensure better adherence to clinical advice. Moreover, approaches such as harm reduction is found to be useful in dealing with chronic substance use and may be better suited to achieve sustainable outcomes rather than traditional methods of compulsory de-addiction.

Advocacy for health care rights and mobilizing for community norm changes will be important ways to deal the issues of HIV especially among disenfranchised populations. Advocacy cannot be imagined as an exclusive activity for a few. Practitioners and clients can make it a part of their basic approach to HIV and health related issues with an aim of expanding the range of available services and enlisting the support of major stakeholders.

### **Implications for Policy**

The study demonstrates the feasibility of a financial incentive program for adherence and identifies key areas through which such a program can work. In terms of scaling up of such a program, our study provides some important insights. First, the incentive works best when provided within a context of other services that help clients with their adherence issues, hence, standalone incentive programs may not succeed. The incentive is an additional benefit that motivates individuals and secures their buy in, it

cannot on itself, overcome the barriers of uneven clinical care, difficulties in access to care, side effects from medicines and other such barriers to adherence. Financial incentives cannot come at the cost of good medical services and as such requires outlays that may not be available in resource limited settings. Second, to allow the positive meaning making processes of improved self-worth, self-care urge, community orientation and future planning, the context in which incentives are provided should be carefully considered. The attitude of care providers towards the clients should not be one of transaction and impersonal service provision. The recipients should not feel stigmatized for receiving incentives (as welfare recipients do in the US) but be made to feel worthy candidates for well-earned rewards. Smaller, community clinics are perhaps best suited for such incentive programs rather than large hospital based clinics where the service is mostly impersonal and does not provide for the non-medical needs of poor clients. Third, social marketing programs and community tailored outreach services may be essential for enrolling and sustaining participants in such a program.

As a conditional cash transfer tool, financial incentives for health and other socially desirable behaviors have been shown to be successful (e.g. *Oportunidades* in Mexico (Fernald, Gertler & Neufeld, 2008)). Financial incentives can become a viable policy tool in supplementing standard income supplementation programs. If adopted as a part of the service packages (and if well implemented) it may not only improve health outcomes, secure buy in and promote sense of self-worth among recipients, it has the potential to help out financially (although in a limited manner) those who are on welfare

benefits. Coupled with budgeting and financial planning trainings it can empower clients to better manage their health care as well as plan their economic futures.

Changing community norms and securing buy in will require more than individual based approaches to behavior change. Structural issues that affect health (poverty, racism, stigma among others) need sustained community level interventions and advocacy to bring about a change in the social and political will. Advocacy and community mobilization, thus, should be an essential part of any health intervention policy especially with marginalized communities.

### **Limitations of the study**

This study was a part of a larger project which qualitatively evaluated the feasibility and effectiveness of VLS intervention. The present study captures a subsection of the data which focuses on understanding the process of financial incentives in promoting adherence to HAART among marginalized PLWHA. A qualitative exploratory study is undertaken to understand the basic concepts involved in a process, and it cannot make claims of definitive causal explanations. Moreover, since the population under study belonged to a very specific category, the clients at an urban HIV-based housing and health service organization, the results remain context specific and cannot be generalized to larger, more diverse populations.

Methodologically, the study had three major drawbacks. First, we relied on the organization to recruit participants. We could not obtain a sample which adequately represented the entire client base participating in the intervention. The responses in the

study are mostly positive towards the program and it may be assumed that only clients who were enthusiastic about the intervention consented to participate in our study. Theoretical saturation was reached, however, a thorough exploration of the “negative cases” or disconfirming evidence (experiences of dissatisfaction with the intervention) could not be carried out. Social desirability bias could have influenced the mostly positive responses from the participants even though it was made clear during the consent process that the research is being conducted by a third party, who will not report any identifiable information to the service providers. Second, due to logistical issues at the time of writing this report we could not perform member check in focus groups as originally planned (we plan to do it in the near future). Third, although we had planned to have multiple researchers look at the results and perform rigor checks such as inter-rater reliability, logistical issues prevented us from doing this extensively. Apart from me, another researcher has gone through the transcripts and we have discussed the codes and themes, but extensive and rigorous inter-rater reliability could not be undertaken.

Another basic issue with conducting this research was the socioeconomic and cultural differences between me, the researcher, and the research participants. Usually this problem of distance between the researcher and the researched is debated extensively in anthropology where ethnographic methods are employed. Moreover, the concerns are more pronounced when the researcher is from a developed country and engages in research in the global south. Here, I, the researcher was from India, a developing country, and came from a privileged middle class background and was

researching participants who were the urban poor in a developed country. Although, I am fluent in the primarily language used by the participants and have received extensive training in the US, the difference in shared references of culture, language and history cannot be entirely overlooked. While it may be never possible to imagine what the results would be if I came from a background closer to that of the participants, efforts were made to be self-reflective and culturally sensitive at every step of the research process. I had spent considerable time with other research projects at Housing Works, and within the limited scope of these interactions, had gained some familiarity and insight as to the organizational and socio-cultural mores of the agency and the clients it serves. By the time I embarked on this particular research project many providers and clients at the agency knew me, hence I was not a rank outsider, but a somewhat familiar research partner. Through the research process, I maintained a research journal where I recorded the settings, mood and details of the interaction that happened before and after the interview. These were my guide to pick up clues about how my presence or interaction was affecting the nature of the interviews. Though such clues or approaches can hardly be systematized, I used this journal to debrief with my mentor and research peers with an aim to detect issues such as leading questions, social desirability, micro aggressions and my attitudes and responses to them. Given that I was the sole researcher, collecting, transcribing, and analyzing the data, there was no way I could blind myself to the details and the person specific contexts of the participants while analyzing their responses. It may be argued, that constructivist grounded theory allows for the co-construction of meaning between the participant and the researcher

(Charmaz, 2006), and blinding processes during analysis which may offer rigor to some other methods of qualitative enquiry, may not be best suited to the purpose of grounded theory.

In the analysis of the data from the interviews we find references to gender, race and socio-economic status issues. For example, an African American man exclaims that the VLS program makes him feel like a “white mama”, transgender women identify a desire to look good as a motivation to self-care, and most participants value the money from the incentive given their fixed incomes. However, the present study does not exhaustively engage with these issues. Given that this was an exploratory study and it sought to gain initial insight into the processes at work to explain the role of financial incentives on adherence, the present study should be viewed as the ground work for further consolidating our knowledge of financial incentives. The underexplored social/structural factors of gender, race and socio-economic status should be delved into in the future research on incentives.

### **Future research**

The next steps to follow up on this initial exploratory study will involve both qualitative and quantitative studies further exploring the connections discovered by this research. Qualitative studies can use the themes from this study and explore their applicability to other more diverse populations within and outside the U.S.A. Further refinement of the themes and their context specificity can be examined through multicenter qualitative study with more diverse participants in different service conditions. As stated in the previous section, social structural factors of gender, race,

socio-economic status need to be explored more fully. Surveys can be developed using the themes elicited through the present study to quantitatively validate the connections indicated by this study. Longitudinal quantitative studies can be designed to explore and substantiate causal claims between motivation and the symbolic and material interpretations of incentives. Intervention programs can be designed with the theory proposed by this study after it has been validated through further qualitative and quantitative research.

### **Conclusion**

The HIV/AIDS epidemic had ushered in a new brand of patient activism in the US which has revolutionized the way public health, biomedical research industry and care providers respond to a new disease. As we enter the fourth decade of the epidemic, large sections of the US population continue to be disproportionately affected by the disease. The availability of effective and relatively safe medicines to control the disease and improve the health outcomes of those affected is an encouraging development. Ensuring adherence to those medications (HAART regimes) has thus emerged as an important challenge in the continuing fight against HIV. Service providers and policy makers are now focused to find new and improved ways to engage and sustain HIV positive individuals in a regime of care to improve their life outcomes with respect to the disease, as well as, prevent the transmission of the virus to the uninfected. Financial incentives, in the context of comprehensive medical and social services, have the capacity to motivate individuals to better adhere to HIV medications resulting in better health and well-being for longer periods of time. Incentives also hold the possibility to

promote, albeit in a very limited way, social equity and intervene at micro, meso, and macro levels of poverty, discrimination and stigma perpetrated by extant systems of welfare, racism and social stratification. Understanding how financial incentives can work will help us to better implement interventions using such a tool. This study was an important step in that effort.



## **Appendix 1: Interview Guide**

### **Interview guide: Qualitative in-depth interviews with VLS clients**

(This is a general guide for the kind of questions to be asked Each theme should be explored, order and the exact nature of questions will vary for each interviewee-interviewer pair )

#### **Introduction**

Introduce yourself. Explain the study, explain confidentiality, seek informed consent.

What is your name? what do you want me to call you during this interview?

How long have you been a client at HW? How long have you been a participant of the VLS/ Undetectables program?

#### **Brief history of experience with HIV**

Do you recall when you first came to know about your HIV positive status?

How did you feel then?

How long ago did you start HIV-meds (HAART)?

How did you feel when you first started the meds?

#### **Issues with adherence**

At present how many pills do you have to take every day for HAART? Can you name them and tell us roughly which do you take when?

Any other medication that you need to take every day?

How difficult or easy do you find taking the medicines every day?

Tell us about some of the challenges.

#### **Intervention and its effects**

Remind me, how long have you participated in the VLS/Undetectable program?

What are some of your experiences with this program?

How do you think it has affected your plans for adherence?

What do you think about the quarterly cash incentives that the program rewards its' participants with?

What do you think people who receive that money, do with it?

Do you attend the adherence groups? When was the last time you attended?

What are your thoughts about the adherence groups?

What are the things you discuss in the adherence groups?

Compare your experience with HW before and after this program.

**Feedback/Recommendations**

Any thoughts on how this program could be different?

Any changes that you would like in the way/amount of the cash incentives are presently set up?

Any changes that you would like to see in the adherence groups?

Any thoughts for your providers (case managers/doctors/therapists) of what they can do differently in this project.

What do you think is working for people who have been able to reach undetectable levels?

What do you think is not working for people who have not been able to do that?

What are the ways in which HW can encourage more clients who are eligible to join this program?

Any other thoughts/ recommendations?

**Appendix 2: Demographic Sheet**

Participant number	
Age	
Gender	
Preferred pronoun	
Race	
Ethnicity	
Year of HIV diagnosis/how many years since diagnosed	
Current status with Viral Load	
Current Housing status	
History of incarceration	
History of substance use	
History of mental health disorder	

### Appendix 3: Notes from the Research Journal

#### Initial codes – line by line, incident by incident

Case workers checking in about adherence - changing focus

“that’s why they have this program because I am not the only one”- feeling less isolated-community feeling” - rightful reward/ not coerced or bribery

“I feel like a white Mama”—racial other privileged bodies/identities desired? Feel better about one’ self? Feel worthy

“I feel much more, much better about it.” - feeling better

“like you brush your teeth so that your breath don’t stink, take those pills so that you do not rot inside”.- integration with daily life

“to know that your health is worth something, you get rewarded for doing a good job with your health”-feeling proud, feeling one has earned it

“I have to do it better now”- motivated

“I am not undetectable and I do not get my card”- anxiety about being in the program? feeling coerced??

“talking about your health, taking your medicines, eating properly, resting, and taking care of your health”-taking care of oneself as part of adherence

“it is like getting the employee of the month”- rightfully earned reward

“Gift card is nice, but my health is more important than a gift card.”—dismissive of incentive? Social desirability

“You end up looking all hollow, your bones show.”- concern about looks

“if you have to get like cosmetic surgery for the breast or bottom surgery, you have to be undetectable”- planning for elective surgeries-healthy behavior for that?

“Like Diabetes or any other condition, it takes us longer to heal”- equating HIV with other chronic disease? Feeling in control?

“I want to live a long and happy life”- desire for longevity

“I can feel a change, I can feel that I will live and remain healthy”- sense of control on future

“I have to live for my dream. I have to keep my health to enjoy the life I want, I can't be dying every day and trying to make by. I need a complete life. I need these meds to work for me.”- life goals – adherence a way to achieve them-ensure longevity

“While I am taking the meds I imagine my grandchild's face”- motivation from family

“I love myself too much to see that happen to me”

“I do not want to end up a walking zombie, a rotten fruit with dry skin over my bones.”- looks? Concern about future looks?

“I want to die happy and drunk, not sad and clean”- hopeless and hence careless

“If I do not take the meds I will die”- understanding the role/appreciating the importance of HAART

“The money comes in handy, you know what I mean. 180 dollars every two weeks is tight”- appreciating the material aspect

“I do it for myself, for keeping healthy. I know of some who do it for the money”- bribery? Social desirability

“No one was holding me responsible, asking me about the pills”- norms before the VLS

“Too many things to worry about”- barriers

“I now tell everyone please take your pills, you want to live, right?”- looking out for others in the community

“I took them for some time and then stopped. I was sure nothing will help”- hopelessness

“I saw everyone like me living here and Miss A was so helpful.”- love HW, appreciate the staff

“My partner was in this program, and she told me to join”- enrollment through family/other community members

“You get the reward, you know, one hundred dollars. You will get good care. It is a win-win situation”- appreciating VLS-winning for all, so much winning!

“I am blessed to be a part of this community. I feel I need to give back. I need to tell those who do not know about HIV, I need to spread the word about good health and how happy you can be when you are healthy.”- community feeling

“I mean not just take your own medicines but ask others to do it. I want to be a part of the team” - part of the community, give back to it?

“We can’t stop now. We are so near to the End of AIDS”- movement- advocacy- exceeding individual concern to that of the community

“I get some milk and bread when I get the money. I keep the money for emergency”- material benefit for times of emergency

“I try to save it up for healthy stuff from Trader Joe’s, it is not possible for me to get them otherwise”- material benefit-better food

“sometimes I buy stuff that I need around the house. I got a phone, my phone broke so I got a phone with it. I paid my phone bill the next month”- material benefits, sundry expenses

“One month I had to pay extra for electricity and I had the card, so used some of that”- utilities-material benefits

“I get something big. I got a TV, a blender and a toaster”- luxury goods otherwise too expensive- material benefits

“What I did, I bought a piece of jewelry with my first gift card something to remember you know like why I do, what I do”- rewards, self reward, self worth

“I stopped taking my medication. I was selling it”- selling medication for money- barrier-substance use

“They need their fix and even when they know that my medication is what keeping me alive, I still want my drugs”

“Even if I am not smoking or doing drugs, sometimes I could use that extra money”-- material benefits-patient autonomy

“People forget, people just forget”- forgetting, barrier, demotivated?

“I want to take them every day, like clockwork”- increased self-efficacy

“I just was in the give up stage. I felt that I was going to die anyway”- doubt the efficacy of medicines/hopeless about future

“I did not want to pop it in front of him”- disclosure issues

“I wanted to keep my man”- fear of abandonment- barriers

“My partner had died. That is when everything went downhill”- hopelessness, grief

“I have never seen anything like this. The people of here are amazing”-appreciating HW

“They work with you in trying to solve your issues. I absolutely love it here”- appreciating HW

“They respect you for what you are and then you want to do that for everyone”- community feeling-empowerment-patient dignity

“We are a community of activists here you know”- community feeling, advocacy impulse

“I always telling them to transfer to Housing Works”- enrollment by word of mouth- advocacy

“I like her (his current PCP) better than my doctor in Philly. I used to see him only a few times a year, here she keeps me on my toes”- adherence focused care

“I can tell her that I am not taking my meds because I am stressed” -trust and transparency

“Let me know if you have any trouble with any of the pills. I want you to remain undetectable and get all the reward cards. I feel she always has my best interests at heart”- trust in provider, feeling of partnership

“I would forget, just plain forget, but when I started doing this every day, I remember”- solution to forgetting

“Here is my pill box, I have taken all the medication you know. This makes a difference”- tools- pill boxes help with barriers

Concern with side effects

“I have a friend ring me up. I ring her up too. We check on each other -have you taken the pills? please take them. That’s like having a person care for you”- feeling cared, community feeling, peer support, self care?

“I love them . I want to be in them, my wife has been featured. Yes, she was very proud.”- self worth promotion, social marketing

### **Comparing codes**

Feeling happy with HW- Feeling Happy with one’s self-feel worthy

Feeling rewarded- feeling coerced or bribed

Need to look good- Need to stay healthy- need to be alive for long

Hopelessness- feeling happy with one's self

Taking care of self- feeling happy- feeling rewarded- hopelessness

Barriers-Appreciating HW services

Feeling rewarded- Motivation

Feeling rewarded- Advocacy- Community feeling

Community feeling- hopelessness

Forgetting – Remembering-Appreciating HW

Trust in provider- Appreciating HW- Barriers

Concern with side effects-trust in provider- feeling rewarded-self efficacy

Material benefits- Feeling rewarded-feel worthy

Taking care- Feeling rewarded- Hopelessness- community feeling

Barriers-Hopelessness- Community feeling

### **Emergent categories**

Self-care

Self-worth

Future orientation

Community feeling

Barriers

Appreciating services

Trust based provider relationship

### **Final arrangement of themes into theoretical categories as presented in result**

Motivation –1. Symbolic (self-worth, self-care, future orientations, community orientations)



-2. Material benefits (paying for food, utilities, preventing selling of medication)

Barriers – Hopelessness, forgetfulness, grief, and personal loss, fear of disclosure, side effects

Facilitators-Context of Housing Works, patient-provider relationships, intervention services/tools

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