Antiretroviral Medication Adherence in Shalom Delhi’s Home-Based Care Program

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***Abstract*-HIV/AIDS has been a significant public health issue for India since 1986. The National AIDS Control Organization (NACO) was founded in 1992 to slow the spread of HIV/AIDS in India. By 2004, NACO offered free antiretroviral treatment (ART) to all people living with HIV (PLWH) in India. Due to the program’s success, there was a 71% drop in HIV related mortalities between 1995 and 201****7(Karade 2018).1 However, an estimated 0.21 % of people in India are still living with HIV as of 2017(naco.gov). 2 Despite the availability of ART throughout India, many patients do not participate in the program or adhere to their prescribed treatment. HIV patients generally must have a > 95% adherence rate to maintain a high quality of life (Vallabhaneni 2011).4 In Delhi, NACO provides nine centers where patients go to receive their ART medication, but other organizations provide additional healthcare to HIV patients. Shalom Hospital, a palliative care organization in Delhi, is one such organization. It has a unique Home –Based Care program where trained staff members visit patients throughout Delhi regularly to assess their health and wellbeing. This study was conducted to determine the ART adherence of HIV patients served by Shalom. It was conducted by surveying 80 patients from Shalom’s Home Based Care program. The study assessed the relationship between low adherence and HIV regimen, ART side effects, ART related stigma, and lack of HIV education. This study showed that patients generally are not adherent due to physical side effects or stigma. The purpose of this research project was to raise an awareness of the complications that PLWH taking ART face and to better understand why patients do not adhere to their ART regimen. Taking these factors into consideration, NGOs like Shalom Hospital can modify care protocols to better serve this marginalized population.**

# Introduction

HIV/AIDS has been a significant public health issue for India in 1986. The National AIDS Control Organization (NACO) was founded in 1992 to slow the spread of HIV/AIDS in India. By 2004, NACO offered free antiretroviral treatment (ART) to all HIV/AIDS patients. Due to the program’s success, there was a 54% drop in HIV related mortalities between 2004 and 2015 (Karade 2018).1 However an estimated 1.71 million people in India are still living with HIV(naco.gov).2 Despite the provisions of ART throughout India, many patients do not adhere to their treatment (nacp.gov).3 HIV patients generally must have a > 95% adherence rate to maintain a satisfactory quality of life (Vallabhaneni 2011).4 In Delhi .30 % of the population is still HIV positive (naco.gov).2 NACO currently provides nine centers throughout Delhi where patients receive their ART medication (naco.gov).2 Because HIV/AIDS care is holistic and not limited to medication Shalom’s Home Based Care program visits patients in Delhi regularly to assess their health and wellbeing (nacp.gov).3 Studies have shown that factors including medication side effects, medication accessibility, stigma, and HIV education contribute to a patient’s likelihood of adherence. Unlike most studies, this study will be conducted in Home Based Care patients’ homes to allow for patient authenticity and comfort. This study also aims to quantify the term “social stigma” in a unique way, by assessing the various aspects of a patient’s society including family, community, and healthcare providers relationships.

Shalom Hospital is a palliative care unit of the Emmanuel Hospital Association, a network of non-profit, Christian hospitals located throughout Northern India. Shalom is specifically committed to caring for people who are living with chronic and life-limiting illnesses such as HIV/AIDS and cancer. Shalom seeks to consider the whole person when caring for patients as they address the physical, mental, emotional, spiritual, and social needs of both their patients and their families (shalomdelhi.org).5

The objective of this study was to determine levels of adherence to antiretroviral treatment for patients involved in Shalom Hospital’s Home-Based Care program. Additionally, I wanted to determine if adherence was decreased due to social stigmas, medication side effects, and lack of education regarding HIV and antiretroviral treatments. The specific aim of this study was to gain knowledge about patients involved in the Home-Based Care program and better understand medication adherence and reasons for lack of adherence.

# Methods

This study was conducted by obtaining survey information regarding adherence rates among patients. Using a survey tool which I administered in Hindi, I sought to identify whether patients are adhering to their medication and some of the potential reasons for lack of adherence. I also asked questions regarding patient demographics, medication adherence, social stigma, side effects, and knowledge of HIV and HIV treatment. The results of this study will provide Shalom with information about how they effectively come alongside patients, and how they might encourage patients who are struggling with medication adherence.

The Shalom HBC team visits patients either once a month, or once every two months. The interviews were conducted in Hindi during these routine visits following an explanation of the study by an HBC team member and receiving the patient’s consent. The study was conducted in the patients’ homes, in the presence of HBC team members. During the visit, an unannounced pill count also occurred. This was done with the patient’s consent in an attempt to receive accurate information regarding a patient’s adherence. In accordance with Shalom Hospital’s standards, adherence was classified as taking medication 100% as prescribed.

The data were recorded on sheets that contained the survey in both English and Hindi. The information from the surveys was entered into a password-protected computer document in Microsoft Excel. Following the completion of all surveys data were analyzed using ANOVA, chi squared, and regression analysis with JMP software.

# Results and Discussion

According to the pill count, 21.3% (n=17) of patients were adhering to their prescribed medication doses, while 83.7% (n= 67) of patients were not adherent. In contrast, 66.3% (n=53) of patients reported that they were adhering to their medication, while only 33.7% (n=27) reported that they were not adhering to their medication. When these two variables were compared by running a chi-squared test, the differences between pill count and self -reported adherence were found to be statistically significant (X2=4.99; df=1; p=0.0204). Additionally, 53.7 % (n=43) of patients were not adherent by pill count, but were adherent by self -report, while only 20 % (n=16) were adherent by both pill count and self-report.

More than half (n=42) of patients reported that they were experiencing physical side effects. The most commonly reported types of physical side effects were nerve pain (n=16), dermatological side effects (n=6), wasting/lipodystrophy (n=5), musculoskeletal pain (n=4), and weight change (n=3). 83% (n=35) of patients who reported experiencing physical side effects were not adherent to their medication according to pill count. Only 16.7% (n=7) of patients experiencing physical side effects were adherent to their medication according to pill count.

Half (n=40) of patients reported that they were experiencing HIV-related stigma. Of these patients, 55% (n=22) reported feeling stigma from healthcare professionals, while 45% (n=18) reported feeling stigma from community members and 40 % (n=16) reported feeling stigma from family members. When asked whether experienced stigma impacted their adherence to antiretroviral treatments, 47% (n=19) of patients stated that it did. When a chi-squared test was performed to compare the impact of

stigma on ART adherence, it was found to be statistically significant (X2=4.735; df=1, p=0.0292).

Most of the patients (n=72) stated that they had received education about HIV upon diagnosis. When asked quiz questions related to HIV transmission, 83% (n=66) of patients answered the question correctly. There was no notable correlation between HIV education and ART adherence.

We found an inconsistent story regarding antiretroviral treatment adherence. When we determined adherence based on pill count, only 21.3% of the population was adherent, but when asked, 66.3% self- reported adherence. These percentages were much lower than anticipated by Shalom’s staff yet were expected based on other studies that have been conducted on antiretroviral treatment adherence in India (Cauldbeck 2009,Acchappa 2013). 6,7 Utilizing both pill count and self-reported adherence methods as a part of this study was intended to bring about more well-rounded results yet turned out to create a statistically significant disparity that was not anticipated. A study conducted by Pahari et. al (2015) in West Bengal, India in 2015 faced similar difficulties when pill count varied from self-reported adherence, with patients (Pahari 2015).8 Because neither method for measuring adherence is completely accurate, it is difficult to certainly know the adherence rates of the patients involved in this study, as patients have a tendency to be optimistic about adherence and pill counts tend to be inaccurate (Vallabhanenia 2011).4 However, results do show that 23.7% of patients (n=19) were not adherent by pill count or self-report, which shows that a notable portion of the patients involved in Shalom’s Home-Based Care Program are not able to adhere to their antiretroviral medication. Many researchers have struggled to find accurate and affordable ways to measure adherence to antiretroviral medications which puts smaller hospitals like Shalom at a disadvantage, as it is difficult for them to have an understanding on the adherence levels amongst their patients. A 2015 article by Platt et. al suggests the use of multiplex cathepsin zymography as a way to use low- cost electrophoresis-based assays to measure the amount of cathepsin activity, which has shown to be a biomarker for ART adherence (Platt 2015).9 Developing more accurate and affordable measures of adherence could change the future of ART adherence research. If hospitals and clinics like Shalom were able to utilize multiplex cathepsin zymography as a part of their hospital laboratories, it could potentially be a way that Shalom is able to keep track of adherence amongst patients in their home-based care program.

The purpose of this study was not merely to learn whether patients were adhering to their antiretroviral medication, but also to learn about the possible reasons that they were not adherent. Both physical side effects and stigma were influential factors that impacted patients’ adherence to ART. In our study, 52.2% of patients surveyed reported that they were experiencing physical side effects due to ART. Similarly, a study conducted by Cauldbeck (2009) in Bangalore India showed that physical side effects were seen in 50% of the participants who were not adherent to antiretroviral medication in their study (Cauldbeck 2009).6 In our study, 43.7% of patients surveyed were non-adherent by pill count and also experiencing physical side effects. While there was no significant correlation to which ART regimen produced the most physical side effects, neurological related physical side effects stood out as the most frequent type of physical side effects (n=16). These side effects included physical symptoms such as headaches, tingling sensation in extremities, and difficulty sleeping due to nightmares. Because of the vast range of neurological side effects, it is difficult to devise a specific treatment intervention for them.

Apart from physical side effects the other major factor that influenced patients’ adherence was stigma. 47% of the patients experiencing stigma in this study reported that stigma negatively impacted their adherence to antiretroviral medication. Of the 40 patients who reported experiencing stigma, 22 reported experiencing stigma from a healthcare provider. A 2013 study in South India showed that stigma was reported to be a factor associated with low ART adherence (Achappa 2013).7 Despite the blessing of having access to free antiretroviral treatment, there are still extreme social barriers that PLWH in India face in order to get and take their medicine. Understanding that so many PLWH across the nation of India experience stigma demonstrates how important it is to develop initiatives for reducing stigma for PLWH.

HIV Education was not found to be a factor that significantly impacts ART adherence in this study. Because study participants were associated with Shalom’s HBC program, many of them had been well-educated on the types of questions that were asked on the survey. Most of the patients who answered these questions incorrectly were newly enrolled in the HBC program which is a testament to the HBC program’s commitment to HIV education. Other similar studies conducted on patients already involved in an HIV care program have shown that HIV education does not have a large impact on ART adherence because participants already have sufficient knowledge of HIV (Kumarasamy 2005).10

# Conclusion

The results of this study show that adherence to antiretroviral treatment is sub-optimal, but comparable to other similar studies that have been conducted in India. The disparity reflected in pill count and self-reported adherence shows that there needs to be a more accurate and affordable option for measuring ART adherence, so that organizations like Shalom Hospital can understand patients’ adherence. Physical side effects and stigma showed to have a significant negative impact on patients’ adherence to medication. Continuing to understand the mechanism behind the various ART regimens is integral to continuing to develop better treatment options for PLWH in India. Continuing to counsel, support, and accompany patients the way that Shalom Hospital does will hopefully inspire others to treat PLWH with the respect that they deserve.

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