

# Health Literacy and Treatment Adherence in Hispanic HIV-infected Patients

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## ABSTRACT

*This study examined health literacy in Hispanic HIV infected patients attending two large public clinics in Miami, Florida and assessed its association with adherence to antiretroviral medications. We performed a cross-sectional study. Eligible participants were enrolled from the Jackson Memorial Hospital HIV outpatient clinic and the University of Miami AIDS clinical research facility. Data were derived from socio-demographic information, the adult AIDS clinical trial group (AACTG) adherence questionnaire, the short test of functional literacy in adults (STOHFLA), and information about HIV clinical stages. Questionnaires were completed by study participants or by the study coordinator in their preferred language and the information about HIV stage was obtained from the medical record. Analysis included descriptive, univariate, and bivariate statistics. Sixty patients participated. There were high rates of low health literacy in this group and low levels of adherence to antiretrovirals. However, there was no statistically significant association between health literacy and medication adherence in 30 days or 4 days prior to the clinic visit. Low health literacy was evident in one-third of participants. Health literacy alone was not associated with adherence to antiretrovirals in this sample. Future studies need to identify factors associated with adherence to antiretrovirals in HIV infected Hispanic individuals to improve disease outcomes.*

*Florida Public Health Review, 2009; 6, 62-67.*

## Introduction

In the United States (U.S.) there are racial and geographic disparities in the distribution of patients infected with human immunodeficiency virus (HIV). According to the Centers for Disease Control and Prevention (CDC) surveillance reports (2008), most cases of HIV occur among African Americans, followed by the White non-Hispanic population. Hispanics represent the third largest group of HIV cases in the U.S. In cities with high prevalence of both HIV and Hispanics, such as Miami, most of the cases of HIV occur in African Americans followed closely by Hispanics. In Miami-Dade County in 2007, there were 663 new cases of HIV in African Americans and 593 in Hispanics. These figures represent increases in both ethnic groups compared to the prior year. Whereas the total number of new HIV cases in the U.S. is decreasing, the number of cases in certain minorities such as Hispanics in our county is alarmingly increasing according to the HIV/AIDS Florida Department of Health (DOH) reporting system (2008). Moreover, the number and rates of deaths related to AIDS in Hispanics is also increasing in Miami-Dade County (FDOH, 2008).

It has been clearly demonstrated that the success of antiretroviral medication depends directly on adherence to the prescribed regimen. Failure to maintain strict adherence has been associated with drug resistance and treatment failure that leads to progression to AIDS and death (Altice & Friedland 1998; Eldred, Wu, Chaison, & Moore 1998). Factors

associated with adherence to antiretroviral treatment have been studied extensively and include age, gender, race, level of education, social support, drug or alcohol abuse and psychosocial problems among others (Escobar et al., 2003; Heckman, Catz, Heckman, Miller, & Kalichman, 2004).

Functional health literacy refers to individuals' ability to comprehend medical texts to function as a patient and make appropriate health decisions. Low levels of education and low health literacy have been associated with poor adherence to antiretrovirals in the general population in the U.S. and elsewhere (Escobar et al., 2003; Kalichman, Ramachandran, & Catz, 1999; Kalichman & Rompa, 2000; Wolf, 2007).

We are unaware of any previous studies measuring the association between health literacy and treatment adherence in HIV-infected Hispanic patients. Hispanics may have less understanding of health messages because most messages are provided in English. Many Hispanics speak only Spanish, or have English as their second language. In the study described herein, we sought to determine the level of health literacy in Hispanic HIV-infected patients and evaluate the association between health literacy and adherence to antiretroviral medications in two large HIV clinics in Miami, Florida.

## Methods

### *Design and Settings*

This was a cross-sectional study of HIV-infected Hispanic patients attending two dedicated HIV

clinics located in the Miami Medical Center District in downtown Miami – the Jackson Memorial Hospital HIV outpatient clinic and the University of Miami AIDS Clinical Research Unit.

#### *Inclusion Criteria*

Participants were eligible if they had documentation of HIV infection, were 18 years of age or older, self-identified as Hispanic, and were able to provide informed consent. This study was supported by an unrestricted educational grant provided to Infectious Diseases Fellows by the Bristol Myers Squibb Virology Fellowship Educational Grant Program. The study protocol was approved by the University of Miami Institutional Review Board (IRB) prior to initiation.

#### *Data Collection*

Potential participants were referred by their HIV care providers to the study coordinator who reviewed inclusion criteria and obtained informed consent from eligible patients who agreed to participate in the study. Participants received \$10 in cash as compensation for their time. Data collected included date and place of HIV diagnosis, socio-demographic information, experience with HIV treatment, responses to the adult AIDS clinical trial group (AACTG) adherence questionnaire, responses to the CDC questionnaire “Knowing about AIDS,” and responses to the short test of functional health literacy in adults (STOFHLA). All questionnaires had a validated translation approved by the IRB. HIV disease parameters (CD4 cell counts in cells/mm<sup>3</sup> and HIV RNA viral load in copies/ml) were collected from the participant medical records. Values were those recorded closest day to the study day.

#### *Health Literacy*

Health literacy was measured using the Test of Functional Health Literacy in Adults (TOFHLA). This tool is used to measure functional health literacy - both numeracy and reading comprehension - using health-related materials. It has been used previously in HIV patients to detect barriers to health care. The STOFHLA is a short version of the TOFHLA, developed for screening patient’s health literacy in health care settings (Nurss, 2001). The STOFHLA is a seven-minute self-administered test. It measures reading comprehension using 36 validated questions. Inadequate functional health literacy (score 0-6) indicates inability to read and interpret health texts, marginal functional health literacy (score 7-22) indicates difficulty in reading and interpreting health texts, and adequate functional health (score 23-36) indicates ability to interpret most health texts. We considered patients with low health literacy those who scored 22 or below.

#### *Medication Adherence*

Medication adherence was measured using the AACTG adherence interview. This tool has been used in research settings to measure adherence to antiretroviral medications. Patients are rated according to adherence in the past 30 days (any doses missed versus no doses missed) and number of days without medication in the prior 4 days. The study coordinator assisted the patients in completing this test.

#### *Knowledge about HIV and AIDS*

The CDC knowledge questionnaire contains 15 items and has been used to measure functional knowledge about HIV and AIDS. It is a self-administered test and scores range from 0 to 15.

#### *Data Analysis*

Analysis of the data included descriptive statistics, such as univariate analysis (means, standard deviations, medians) and bivariate analysis of factors potentially associated with adherence. Pearson correlation analysis also was used.

## **Results**

Sixty patients participated in the study. The general characteristics of the patients are described in Table 1. Participants had a mean age of 45 years (range 24-66); 63% were male; and 85% were foreign-born or from Puerto Rico. About one-third of the patients were recruited in the University of Miami research clinic. Most participants (70%) reported heterosexual preference. More than half of the patients had experience with HIV and antiretroviral medications for more than two years. All patients scored less than 80% on the knowledge of HIV/AIDS questionnaire. More than half of the patients had at least high school level of education, but levels of health literacy were low in more than one-third of the patients. Adherence to medication at 4 days and at 30 days was also low (less than one-third of patients had 100% adherence). Viral suppression to <50 copies/ml was achieved in 60% of participants.

Pearson correlation analysis was used to measure the relationship between potential variables associated with adherence at 4 days and at 30 days and with health literacy. No association was found between health literacy measured by STOFHLA and treatment adherence at 30 days ( $p=0.64$ ) or at 4 days ( $p=0.56$ ). The only factor associated with adherence at 30 days was clinic of recruitment ( $p=0.045$ ) – that is patients recruited in the HIV research unit were more adherent. Factors associated with low health literacy were younger age ( $p<0.05$ ), same sex preference ( $p<0.05$ ), lower level of education ( $p<0.05$ ), unemployment ( $p<0.0001$ ) and recruitment in the general outpatient clinic ( $p<0.001$ ).

**Table 1. Description of Hispanic HIV-Infected Patients Included in this Study (N=60)**

Mean Age (years)	45
Gender	
Male	38 (63%)
Female	22 (37%)
Place of birth	
Continental US	9 (15%)
Foreign born, Puerto Rico	51 (85%)
Sexual preferences	
Opposite sex	42 (70%)
Same sex	18 (30%)
Clinic of recruitment	
General HIV clinic	40 (67%)
Research clinic (ACRU)	20 (33%)
Date of HIV diagnosis	
Less than 2 years	15 (25%)
2 to 5 years	11 (18.3%)
More than 5 years	34 (56.7%)
Date of initiation of antiretrovirals	
Less than 2 years	20 (33.3%)
2 to 5 years	12 (20%)
More than 5 years	28 (46.7%)
Employment at the time of recruitment (number, %)	18 (30%)
Education level	
More than high school	33 (55%)
Less than high school	27 (45%)
Substance abuse in the prior 30 days	
Yes	51 (85%)
No	9 (15%)
Adherence in the last month	
100%	31 (51%)
<100%	29 (48%)
Adherence in the last 4 days (number of days without medication), (n=55)	
None	40 (73%)
One day	8 (14.5%)
Three days	2 (3.5%)
Four days	5 (9%)
Health Literacy measured by TOFHLA	
Low (<22)	21 (35%)
Adequate (>22)	39 (65%)
Knowledge about HIV and AIDS	
Less than 50% correct	46 (76.7%)
50% to 80% correct	14 (23.3%)
More than 80% correct	0 (0%)
CD4 count (n=40)	
<200	5 (12.5%)
200 – 350	11 (27.5%)
>350	24 (60%)
Viral load (n=40)	
Undetectable	24 (60%)

## Discussion

Functional health literacy refers to individuals' ability to read and comprehend prescription bottles, appointment slips, and other materials that ensure their successful functioning in the patient role and capacity to make appropriate health decisions. Health literacy is a growing area of interest and is an important consideration for interventions aimed at reducing or eliminating health disparities (Perlow, 2008).

Levels of health literacy in minority populations are thought to be low, but little data is available in Hispanics HIV-infected patients. In other minorities, such as African Americans, both race/ethnicity and low health literacy have been independently associated with antiretroviral adherence, with health literacy functioning as a mediator for the observed relationship between race/ethnicity and poor HIV medication adherence (Osborn, Passche-Orlow, Davis, & Wolf, 2007).

Whereas conflicting results regarding health literacy and its association with treatment adherence in patients with HIV have been published in several studies, most have found an association between the two variables (Escobar et al., 2003; Kalichman, Ramachandran, & Catz, 1999; Kalichman & Rompa, 2000; Wolf et al., 2007). However, in some of these studies, the association seemed to be mediated by other factors such as self-efficacy or level of education (Kalichman, Ramachandran, & Catz, 1999; Wolf et al., 2007). In a longitudinal study of HIV-infected persons with alcohol problems, Paasche-Orlow et al. (2006) did not find such association.

## Summary

We determine the level of health literacy in Hispanic HIV-infected patients in two dedicated, urban HIV outpatient clinics. This sample was composed of mainly foreign-born heterosexual men with education beyond high school. Over half of the sample had preserved immune system (60% of participants) and good virological suppression (60% of participants). We found that over one-third of the participants had low levels of health literacy. Factors associated with low health literacy were younger age, same sex preference, education lower than high school, unemployment and being recruited in the general HIV clinic. In terms of adherence, only about half of the patients had 100% adherence in the prior month and approximately one-fourth of them did not adhere in the prior 4 days.

Contrary to our hypothesis, we did not find an association between low health literacy and poor treatment adherence in Hispanic HIV-infected patients. In our sample, the only factor associated

with treatment adherence was the place of recruitment. Patients receiving HIV care in the clinical research unit were more adherent than the ones attending the large HIV clinic located in the county hospital. This finding could be due to the fact that most of them were enrolled in clinical trials and more ancillary support may have been provided. It also may indicate that patients with higher health literacy may be more willing to participate in clinical trials. Low levels of health literacy in Hispanic HIV patients were previously found in two low income community clinics in Los Angeles (Van Servellen et al., 2003). In that study, the association between health literacy and treatment adherence was not measured but an educational intervention to improve health literacy and evaluate changes in treatment was proposed (Van Servellen et al., 2003). The results of the intervention were successful in improving knowledge and understanding of HIV terms, but no significant changes in adherence were found at six-month follow-up (Van Servellen et al., 2005). In a Boston-based study, 266 HIV patients with alcohol problems were followed during 36 months and the association between health literacy and treatment adherence was measured and a trend was calculated. These patients had low health literacy but there was not an association with adherence or virologic suppression (Paasche-Orlow et al., 2006). In this group, ethnicity was not specified. Our findings, along with those of Paasche-Orlow et al. (2006) and Van Servellen et al. (2005) suggest that efforts to improve health literacy alone may not help Hispanic HIV patients to adhere to antiretroviral drugs. Our study indicates that there is a need for better understanding of the multiple mechanisms that may influence treatment adherence among Hispanic HIV-infected patients.

Assessment of health literacy may be an additional tool needed for the optimal management of Hispanic patients with HIV infection. We believe that improving health literacy in combination with other factors such as poverty, level of education and drug abuse may have a benefit. Focusing on improving health literacy alone may not be an optimal strategy.

This study has several limitations:

- The main limitation was the size of the sample. It was estimated that a sample of 200 participants was needed to obtain adequate statistical power. For logistical reasons, the sample the study only included 60 participants. The response rate was high, and therefore, we did not compare data of participants and non-participants.

- The second limitation was the method of evaluation of adherence. We used only a self-reported validated questionnaire and no other tools such as pill counts or other corroborating questionnaires. The reliance on self-report alone may have reduced our ability to detect actual variation in adherence levels.
- Third, health literacy was measured using the short version of the TOFHLA. Administering the full version, or measuring health literacy with another validated screening tool, may have yielded different results.
- Fourth, generalization of these results may be limited because the patient sample was obtained from a single city.
- Fifth, it is always possible that potential participants with very low health literacy may have refused to enter the study due to recognition of their vulnerability. However, the magnitude of this self-selection bias would be small because the response rate to participate in the study was high.
- Lastly, the inability to assess the possible role of language barriers in the clinic was not assessed. We did not control the rate of referral to the study by provider's language. Our clinic is a multicultural clinic and the language of communication with patients is variable depending on provider's ability to speak Spanish.

## Conclusions

We found no association between health literacy and adherence to antiretroviral medications in this group of HIV-infected Hispanic patients. Additional studies are needed to understand other possible factors that influence adherence to antiretroviral drugs in Hispanic HIV-infected patients.

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