CHALLENGES TO ANTIRETROVIRAL ADHERENCE: HEALTH BELIEFS, SOCIAL SUPPORT AND GENDER ROLES IN NON-ADHERENT MEN LIVING WITH HIV IN PUERTO RICO

Karen Nieves-Lugo and José Toro-Alfonso
Departamento de Psicología, Universidad de Puerto Rico

ABSTRACT

With the introduction of the highly active antiretroviral therapy treatment (HAART), HIV-related mortality and morbidity have dramatically decreased in countries with access to the medications. In terms of HIV treatment, adherence has become a major public health concern. In order to reduce HIV-related illness and HIV transmission, proper adherence is required and extremely desired. Understanding issues related to non-adherence is important for the development of appropriate interventions. Addressing the factors of health beliefs, social support and the influence of masculine gender roles regarding non-adherence behavior to HIV therapy is relevant for health psychology. In this study, we examined non-adherence behavior in a convenience sample of 124 men living with HIV/AIDS in Puerto Rico. Participants perceived low levels of social support. Most of our participants showed moderate adherence to traditional gender roles and positive health beliefs. Adherence to treatment is a complex behavior that is affected by numerous psychological, sociological and biomedical realities. Implications for possible interventions are discussed.

Keywords: HIV/AIDS, Health Beliefs, Social Support, Gender Roles, Adherence
INTRODUCTION

Since the introduction of the highly active antiretroviral therapy treatment (HAART), HIV-related mortality and morbidity have dramatically decreased in countries with access to HAART medications (Cardarelli, Weis, Adams, Radaford, Vecino, and Munguia, 2008). HAART has transformed the HIV disease into a manageable chronic disease. Nevertheless, living with a chronic disease requires adjustment across multiple life domains, which unfolds over time and has been shown to have a broad heterogeneity across individuals (Stanton, Revenson, and Tennen, 2007). Someone’s personal resources and individual life events, as well as how the person assigns cultural meanings, likely combine to shape how he or she appraises and responds to the experience of living with HIV (Gibbs, 2005).

As a chronic disease, HIV requires the use of HAART for an undetermined amount of time. The aim of HAART is to suppress the replication of HIV to the point of reaching undetectable levels, and its successful outcomes depend largely on medication adherence (Schönnesson, Williams, Ross, Diamond, and Keel, 2007). Adherence rates vary as a function of illness severity and the patient’s perception of the effect that their adherence is likely to have (Godwin-Rabkin and Chesney, 1999). Adherence to HAART often represents a complex and demanding set of challenges. Although newer formulations of HAART often require both fewer pills and fewer dosing times, the behavior can still be a demanding one in light of the other medical, psychological, sociological and economic burdens that people living with HIV face (Halkitis, 2002).

Medication adherence is a significant public health problem, particularly among persons living with chronic health conditions (Woods, Dawson, Weber, Gibson, Grant, and Atkinson, 2009). It has been estimated that as many as 50% of participants in a clinical trial for chronic disorders may not adhere to their prescribed medication regimens (Osterberg and Blaschke, 2005). Factors associated with non-adherence across numerous chronic disease states, including HIV infection, have included compilations of attributes and circumstances and have been frequently reported in scientific literature (Grodesky, 2006).

Although men had previously dominated epidemiological research, the study of gender and health has recently been predominantly focused on women’s health, to the point of, at least in relative terms, practically ignoring men’s health (Courtney, 2001). Men’s health has emerged as an important public concern that may require new ways of health care intervention and increased resources (Schonfield, Connell, Walker, Wood, and Butland, 2000). Since the beginning of the HIV epidemic in Puerto Rico, men have been the most affected group. In Puerto Rico, through September 2010, the AIDS Surveillance Program has reported 25,707 cases of men living with AIDS (Puerto Rico Department of Health, 2010). Of these, 53% reported acquiring HIV through injection drug use and 36% through sexual contact (men who have sex with men accounted for 22% and heterosexual contact, for 14%).

The literature has stated that the process of gender role socialization establishes men’s attitudes, beliefs, and health-related behaviors (Malalik, Burns, and Syzdek, 2007). Men’s health is affected by the construct of masculinity, which is the socio-cultural and psychological process of learning and adhering to the standards of becoming a man (Habben, 2005). Garfield, Isacco, and Rogers (2008) indicated that men who hold more to traditional beliefs about masculinity and male gender roles are more likely to smoke, to have poor
dietary and sleeping habits, and to have a greater risk for physical injury due to accidents, compared with men who do not adhere to traditional gender roles.

Gibbs (2005) indicated that a chronic illness can involve pain, fatigue, and reduced strength and flexibility, thus undermining the image of strength and independence that is associated with hegemonic masculinity and the factors that traditionally sustain a man’s place in the gender order. She has investigated men’s experiences and factors influencing the use and management of health care services in a sample living with severe arthritis, which is considered a chronic disease. The author concluded that increasing severity of pain and physical limitations affected men’s capacity to work, socialize and maintain their roles in relation to partners and friends, resulting in a rejection or reformulation of hegemonic masculinity in order to make sense of their own circumstances.

An important factor that has been documented to have the effect of enhancing adherence to HAART is the availability of social support. Investigations into the benefits of social support have documented a positive impact in terms of mood, quality of life and feelings of empowerment among people living with HIV (Carrobles, Remor, and Rodriguez-Alzamora, 2003; Toro-Alfonso and Varas-Diaz, 2004). The variable of social support may have three forms of expression: instrumental (that is, providing material assistance aimed at solving a problem), informational (providing information, advice and guidance in the process), and emotional (expressing affection, empathy, love, understanding, and support) (House, 1981).

In situations of chronic illness, expressions of social support prolong life and improve health conditions with positive influences that encourage healthy behaviors. Toro-Alfonso and Varas-Diaz (2004) indicated that social support networks have serious implications in the health of people living with HIV. Quiceno, Vinaccia, Lozano, Castaño, and Fernández (2008) found that people living with HIV considered that the staff at clinical center to be one of the most important sources of social support followed by relatives, because it was through clinical center personnel that they obtained information on how to manage their treatment. Also, Remien (2002) found that social support can be a significant factor in enhancing adherence to health care directives and HIV antiretroviral therapies if the support comes from spouses or primary partners.

Health beliefs make up another factor that is associated with adherence to HAART. Individual’s health beliefs are important for following treatment behaviors (Glanz, Lewis, and Rimer, 1997). Studies have found that beliefs about the illness are associated with levels of adherence and management strategies of the condition (Cabassa and Lagomasino, 2008; Hagger and Orbell, 2003; Petrie, Jago, and Devich, 2007). For these reasons and in order to provide an adequate health care service, it is useful for providers to be familiar with the beliefs patients have about the treatment and how they manage their treatment. It is becoming clear that each person living with HIV develops his/her own understanding of what an illness means, and that that understanding influences self-care behaviors including adherence behavior (Reynolds, 2003). The beliefs that people living with HIV have about their illness helps to predict psychological well-being and levels of depression (Carrico, Antoni, Durán, Ironson, Penedo, and Fletcher, 2006). Schönnesson et al. (2007) found that patients who reported medication side effects expressed distrust in the benefit of HAART. Gao, Nau, Rosenbluth, Scott, and Woodward (2000) investigated the effect of disease severity and health beliefs on medication adherence among HIV/AIDS patients. Their study found that perceived susceptibility to illness and perceived barriers to treatment (i.e., difficulty following the doctor’s instructions) were both significantly related to medication adherence.
Social and psychological factors are among the most significant factors that influence adherence to therapy (Gonzalez, Penedo, Antoni, Fernandez, McPherson-Baker, and Ironson, 2004). Some factors that have been shown to be associated with adherence behavior are: age, sex, educational level, substance abuse (alcohol and illegal drugs), psychological factors (depression, anxiety and stress), social support, and gender, among others (Carrobles et al., 2003; Cook, Grey, Burke-Miller, Cohen, Anastos, and Ghandi, 2006; Levine, Hinkin, Castellon, Mason, Lam, and Perkins, 2005; Moreno, Garcia, Rodriguez, Diaz-Gonzalez, Robles, and Frias, 2007; Poupard, Ngom-Gueye, Thiam, Ndiaye, Girard, and Delaporte, 2007; Negrón-Chaves, García, and Martínez-Taboas, 2005; Remor, Penedo, Shen, and Scheniderman, 2007; Siegel and Schrimshaw, 2007; Sikkema, 1998; Varas-Diaz and Toro-Alfonso, 2003). Nevertheless, no combination of variables has shown to consistently identify either those who will or those who will not adhere to treatment regimens they initially agreed to follow (Godwin-Rabkin and Chesney, 1999).

**OBJECTIVES**

Using health beliefs theory, this study aimed to describe the non-adherence behavior in a group of men living with HIV infection in Puerto Rico and to evaluate the role of social support and the influence of masculine gender roles and health beliefs in non-adherence behavior to HIV therapy.

**METHOD**

Participants

This cross-sectional study was conducted with an available sample of 200 participants recruited from six local clinical centers or community agencies that serve people living with HIV in Puerto Rico. The inclusion criteria for participants were as follows: 1) Men who were more than 21 years old and, 2) Were currently prescribed with HIV treatment. This analysis was a sub-study of a larger research that examined the relationship of gender roles, depression, social support, stress-related to treatment and health beliefs with adherence to HIV therapy in a group of men living with HIV. The current analysis included 124 participants that showed non-adherence behavior.

The mean age was 45.7 years (range 23-69). Most of the participants (81.7%) were living in metropolitan areas of Puerto Rico. Regarding their income, 65.2% were living on less than $9,999 a year, followed by 21.7% living on between $10,000 and $19,999 per year. By Puerto Rico’s standards, these incomes fall on significantly low levels. The most frequent route of HIV transmission in the sample was sexual contact: heterosexual sex (31.1%) and men who have sex with men (31.1%), followed by drug injection (20.2%). Sixty-eight percent (n = 80) of participants reported receiving psychological therapy, and 40.2% (n = 47) reported receiving therapy for depression disorder with a psychiatrist or psychologist professional. Participants did not show depressive symptomatology. Table 1 shows the demographic, disease and psychological information of the group.
Table 1 Participant’s demographic, disease and psychiatric characteristics

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Frequency (%)</th>
<th>Disease characteristics</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual Orientation</td>
<td></td>
<td>HIV Diagnoses</td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>81 (66.4)</td>
<td>≤ 5 years</td>
<td>22 (18.5)</td>
</tr>
<tr>
<td>Homosexual</td>
<td>35 (28.7)</td>
<td>6 to 14 years</td>
<td>55 (46.2)</td>
</tr>
<tr>
<td>Bisexual</td>
<td>6 (4.9)</td>
<td>≥ 15 years</td>
<td>42 (35.5)</td>
</tr>
<tr>
<td>Educational Level</td>
<td></td>
<td>HIV therapy</td>
<td></td>
</tr>
<tr>
<td>≤ High school Diploma</td>
<td>32 (25.8)</td>
<td>≤ 5 years</td>
<td>31 (25.4)</td>
</tr>
<tr>
<td>High School Diploma/Equivalent</td>
<td>39 (31.5)</td>
<td>≥ 6 years</td>
<td>91 (74.6)</td>
</tr>
<tr>
<td>Associate/Technical Degree</td>
<td>29 (23.4)</td>
<td>CD4+ cell count</td>
<td></td>
</tr>
<tr>
<td>Bachelor Degree or Graduate Education</td>
<td>24 (19.0)</td>
<td>Aware</td>
<td>69 (55.6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unaware</td>
<td>55 (44.4)</td>
</tr>
<tr>
<td>Health Insurance</td>
<td></td>
<td>Viral Loads</td>
<td></td>
</tr>
<tr>
<td>Government</td>
<td>93 (75.0)</td>
<td>Aware</td>
<td>51 (41.1)</td>
</tr>
<tr>
<td>Private</td>
<td>13 (10.5)</td>
<td>Unaware</td>
<td>73 (58.9)</td>
</tr>
<tr>
<td>Other</td>
<td>18 (14.5)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Psychiatric characteristics

<table>
<thead>
<tr>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-reported having received treatment for</td>
</tr>
<tr>
<td>Depression</td>
</tr>
<tr>
<td>Anxiety</td>
</tr>
<tr>
<td>In a year, frequency of psychological therapy</td>
</tr>
<tr>
<td>No psychological therapy</td>
</tr>
<tr>
<td>Weekly</td>
</tr>
<tr>
<td>Monthly</td>
</tr>
<tr>
<td>Every three months or more</td>
</tr>
<tr>
<td>Substance use in the past 30 days</td>
</tr>
<tr>
<td>Alcohol</td>
</tr>
<tr>
<td>Tobacco</td>
</tr>
<tr>
<td>Methadone</td>
</tr>
<tr>
<td>Marijuana</td>
</tr>
<tr>
<td>Cocaine</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Received services for alcohol or drug abuse</td>
</tr>
<tr>
<td>Drugs</td>
</tr>
<tr>
<td>Alcohol</td>
</tr>
<tr>
<td>Both</td>
</tr>
</tbody>
</table>

Variables and Measures

Participants were asked to complete a self-administered questionnaire that included questions on sociodemographic, disease, substance use and psychiatric characteristics. Also, the following scales were administered: adherence assessment, social support perception, stress-related to treatment management, health beliefs, adherence to traditional gender roles and depressive symptomatology. The variables of interest for this analysis are adherence, health beliefs, social support and gender roles.
1. **Adherence.** Medication adherence was defined as *a patient takes the prescribed dose of the medications per schedule and following dietary instructions* (HRSA, 2008). Adherence to treatment was measured using the Simplified Medication Adherence Questionnaire (SMAQ), which has been validated for Spanish population by Knobel and his collaborators (2002). Knobel and collaborators designed the SMAQ based on the Morisky scale, which has previously been proved easy to integrate into a standard medical visit. The scale contains the following questions: 1) Do you ever forget to take your medicine?; 2) Are you careless at times about taking your medicine?; 3) If at times you feel worse, do you stop taking your medicine?; 4) Did you not take any of your medicine over the past weekend?, and 5) Thinking about the last week, how often have you not taken your medicine?

The response options were dichotomous (yes or no) for the first four questions. To classify a participant as adherent his answers had to be: 1) No, 2) Yes, 3) No, 4) No, and 5) Never or one to two times. Any response in the sense of non-adherence was considered non-adherent. Participants were classified into two groups, those who were adherent and those who were non-adherent to the HIV treatment. In addition, we asked participants to choose the possible reason or reasons for missing or discontinuing the use of the medication (s) and the strategies they use to remember taking a dose, the time dealing with the disease. Additionally we asked about the length of time using HIV therapy and how many times their medication was changed.

2. **Health belief.** Health beliefs were measured by an 11-item scale, which was constructed by the first author of this article. Belief was defined as the interrelation of someone's perception of susceptibility to a particular illness, his/her perception of the probable severity of that illness and his/her evaluation of the advocated health behavior in terms of it is feasibility and efficacy (Rosenstock, 1966). The health beliefs questionnaire items were presented in a Likert-type format of five-answer options, from strongly disagree (5) to strongly agree (1). A content validity with three judges was performed. The maximum score obtained by participants on this scale was 55 points. The scale was interpreted to mean that a higher score indicated positive health beliefs; participants with scores higher than 27 have more positive health beliefs. The Cronbach’s alpha internal consistency coefficient for this scale was 0.82.

3. **Social Support.** The perception of social support was assessed using an 11-item scale developed by the first author of this article. The scale was based on the Medical Outcomes Study (MOS) Social Support Scale developed by Donald and Stewart (1991). The items were designed to measure the functional components of social support. The functional components of social support were measured according to the degree to which interpersonal relationships served particular functions, according to the participant. Three functions were evaluated: 1) Emotional support, which involves the expression of positive affect, empathetic understanding and the encouragement of expressions of feelings; 2) Informational support refers to the offering of advice, information, guidance or feedback, and 3) Tangible support is the provision of material aid or behavioral assistance. The response options are rated on a four-point scale, ranging from 1 (none of the time), 2 (some of the time), 3 (most of the time) and 4 (all of the time), with higher scores representing a perception of more social support.
In addition, three questions were designed to assess the size and density of the support network. The size is the number of people who provide support, while density is the degree of interaction between the people who provide support. The questions were: 1) How many people do you have to assist you with your problems related to the HIV status?; 2) From which of the following persons are you receiving support?; and 3) In general, how satisfied are you with the regularly received support? The response options were 1 (unsatisfied), 2 (slightly satisfied), 3 (somewhat satisfied) and 4 (very satisfied). The total score was calculated using the mean, which was computed as the sum of the items divided by the number of items answered (this accounted for missing data). Cronbach’s alpha internal consistency coefficient for this scale was 0.94.

4. **Gender roles.** The scale designed by Toro-Alfonso and Varas-Diaz (2003) was used to measure adherence to traditional gender roles. The scale was based in the Male Role Norms Inventory developed by Levant and Fisher (1998). This 33-item survey assesses both traditional and non-traditional masculinity ideology. The response options are rated on a five-point Likert-type scale, ranging from 1 (strongly disagree) to 5 (strongly agree), with higher scores representing stronger adherence to traditional gender roles. The maximum score obtained on the scale was 165 points; higher scores mean stronger adherence to traditional gender roles. Participants were grouped into three categories: low adherence to traditional gender roles (0-54), mild adherence to traditional gender roles (55-108) and high adherence to traditional gender roles (109-165). Cronbach’s alpha internal consistency coefficient for this scale was 0.94.

**Procedure**

The design of the study was approved by the Institutional Review Board (IRB) of the University of Puerto Rico, Rio Piedras Campus. Written informed consent was obtained from each subject before admission to the study. Then, participants completed the self-administered questionnaires. Assistance to complete the questionnaires was provided to those participants who requested it. The time to complete the questionnaires oscillated between 40 to 60 minutes. We recruited participants until the sample size was completed.

**Data Analysis**

The aim of this analysis was to describe the characteristics of a sample of non-adherent men to HIV therapy. Descriptive statistics were computed for all variables. Frequencies and percentages are provided for category variables, and means and standard deviations are provided for continuous variables. Independent samples t-test, ANOVA and chi-square were performed to test differences in health beliefs, social support and gender roles, and sociodemographic characteristics as well. If an expected cell count was lower than five, Fisher’s exact test was used instead of chi-square. The variable education was re-coded into four categories: less than High school Diploma, High School Diploma/Equivalent, Associate/Technical Degree and Bachelor’s or Graduate Degree. Sexual orientation was
dichotomized as heterosexual and homosexual. All statistical significances were two-tailed ($p < 0.05$). The statistical analysis was carried out using SPSS, version 17.0 for Windows.

**RESULTS**

**Use of Medication**

Participants showed contradictory behavior using medications. More than two-thirds of the participants (84.7%) reported in the adherence scale that they sometimes forgot their medication. Meanwhile, 28.2% of the participants forgot to take it during the weekends, and 37.1% did not take the medications due to their side effects. Although these participants did not show proper adherence to treatment, 61.3% indicated that they took the pills on time.

When we asked for the possible reason for missing or discontinuing the use of their medication, the most common reason reported was that they forgot to take the pills (26.7%), followed by other reasons (11.9%) such as: I don’t take the pills on weekends. It happens to me when I have trouble with the eating time, and I should take the pills with food. When I sleep in a friend’s house, I don’t take the pill. I have problems refilling the medications prescriptions or with the health care plan. I forgot the medical appointment. I do not like taking the pills. I do not take the right dosage to have enough pills when I travel and I have ulcers or I vomit when I take the medication (see Figure 1).

![Figure 1](image1.png)

Figure 1. Reasons for missing or discontinuing the use of the medication(s).

![Figure 2](image2.png)

Figure 2. Strategies used to remember taking the medication.
Participants reported using multiple strategies to remember taking their medications (see Figure 2). More than half of participants remember to take medications by memory, whereas 21.5% use a pillbox. Other strategies used by participants to recall taking the medication were: The nurse from the home gives me the pills. Because the pills are once a day, I take them with breakfast. I schedule to take the medication at bedtime. I put the medication in a visible place. I take the medication when I get up and at bedtime, and Habits.

Health Beliefs

Participants showed positive health beliefs, with an average of 39.84 (SD = 11.20). We examined whether there were differences in participant’s health beliefs as a function of educational level. The group of participants who did not complete high school had lower averages than participants who had completed high school or attained a higher educational level (see Table 2). There was an association between health beliefs and education ($\chi^2_{[3]} = 22.019; p = 0.000$), with awareness of their CD4+ cell count ($\chi^2_{[1]} = 10.779; p = 0.001$) and with awareness of their viral loads ($\chi^2_{[1]} = 8.554; p = 0.003$). No differences were found between health beliefs and years living with HIV ($\chi^2_{[2]} = 0.411; p = 0.814$) or with years using the therapy ($\chi^2_{[1]} = 1.052; p = 0.305$).

Table 2. Means and standard deviations of health belief averages by educational level

<table>
<thead>
<tr>
<th>Category</th>
<th>N</th>
<th>Mean ± SD</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; High school Diploma</td>
<td>30</td>
<td>25.50 ± 11.85</td>
<td>4.00</td>
<td>53.00</td>
</tr>
<tr>
<td>High School Diploma Equivalent</td>
<td>39</td>
<td>32.87 ± 9.06</td>
<td>3.00</td>
<td>54.00</td>
</tr>
<tr>
<td>Associate/Technical Degree</td>
<td>29</td>
<td>35.86 ± 8.58</td>
<td>18.00</td>
<td>49.00</td>
</tr>
<tr>
<td>Bachelor’s Degree or Graduate Education</td>
<td>24</td>
<td>35.88 ± 9.43</td>
<td>11.00</td>
<td>53.00</td>
</tr>
</tbody>
</table>

More than half of the participants (53.4%) strongly agreed with the statement: I stopped taking my medication because the HIV treatment is hard to follow, and 28.6% strongly agreed with the item: The drug’s side effects limit my social activities. Nearly of thirty-two percent of participants agreed that their illness causes physical pain. However, 30.4% of participants disagreed with the statement: My illness causes physical fatigue. Disease symptoms, medication side effects and the complicated itineraries to take the medication are factors that could cause participants not to use the pills.

Thirty-eight percent of participants did not feel uncertainty about their future, and 44.8% did not consider that taking medications reminded them that they have HIV. On the other hand, 27.1% were worried by the fact that other persons could discover they have HIV because they have to take medications regularly. Almost thirty percent of participants agreed that the HIV treatment has unpleasant side effects. These tendencies were maintained when factoring in the increase in years living with the condition and using therapy. On the other hand, participants expressed that taking the medications benefits their health. Almost thirty
percent of participants disagreed with the statement *Taking my medications reminds me that I have HIV*. For 44% of these men, the HIV treatment did not harm their bodies.

**Social Support**

Social support is an important factor for adherence to medications. Participants perceived low levels of social support. The mean and standard deviation for the social support scale were 2.73 and 0.974, respectively. In terms of tangible support, these men indicated that they did not have a person that helped them with household work (48.7%). Likewise, they did not have anyone to assist them in attending medical appointments (53.9%) or with refilling their medication prescriptions (45.2%).

Most of them indicated that they had a person that provided emotional support. Some reported to have someone all the time to show them expressions of love and affection (42.2%). They had someone to share social activities with, such as: going to the movies or going to dinner, among others (35.6%). Table 3 presents the averages obtained by participants per item of the scale. When we asked, in general, how satisfied they were with the help received, 46% of them indicated that they feel very satisfied, and 38.1% feel somewhat satisfied with the support they have received.

<table>
<thead>
<tr>
<th>In the last 30 days do you have someone to</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>... show you expressions of love or affection.</td>
<td>2.77 ± 1.240</td>
</tr>
<tr>
<td>... talk to when you feel fear about your future.</td>
<td>2.25 ± 1.220</td>
</tr>
<tr>
<td>... talk about the use of the medication.</td>
<td>2.05 ± 1.200</td>
</tr>
<tr>
<td>... give you support to fulfill the treatment.</td>
<td>2.47 ± 1.304</td>
</tr>
<tr>
<td>... look for information about HIV treatments.</td>
<td>2.21 ± 1.273</td>
</tr>
<tr>
<td>... share with you in social activities.</td>
<td>2.53 ± 1.245</td>
</tr>
<tr>
<td>... offer you advice to fulfill the HIV treatment.</td>
<td>2.13 ± 1.271</td>
</tr>
<tr>
<td>... help you with the housework.</td>
<td>2.16 ± 1.300</td>
</tr>
<tr>
<td>... pick up the medications at the pharmacy.</td>
<td>2.12 ± 1.244</td>
</tr>
<tr>
<td>... assist you in attending your medical appointments.</td>
<td>2.03 ± 1.267</td>
</tr>
<tr>
<td>... help you with daily chores if you were to get sick.</td>
<td>2.23 ± 1.340</td>
</tr>
</tbody>
</table>

In addition, they indicated that all people living with them know about their diseases. Eleven percent of the participants reported that they lived in assisted living homes, drug rehabilitation facilities, with an aunt or uncle, or with a sibling (Figure 3). In addition, we explored who assisted the participants with the management of their illness. More than half of the participants received regular support from their partners or parents. Figure 4 illustrates participant's relationship to the people who offered them support. Ten percent (10%) of participants reported that they received support from the clinical centers' case managers, from people that live or work in the assisted living homes, or from daughters, sons, in-laws and past-partners.
Most of our participants showed mild adherence to traditional gender roles (Figure 5). We explored whether there were differences in adherence to traditional roles by education, sexual orientation and years living with HIV. There was no association between traditional gender roles and education ($p = 0.085$) or between traditional gender roles and years living with HIV ($p = 0.592$). However, we found differences in adherence to traditional gender roles by sexual orientation ($t_{110} = 3.164$; $p = 0.002$). The average scores obtained by men that were self-identified as heterosexual was $93.54$ (SD = 24.486) and for men that self-identified as homosexual was $79.20$ (SD = 20.776).

Participants showed adherence to traditional gender roles regarding the statements indicating that men are the stronger sex. We found that $34.2\%$ of men strongly disagreed and $21.4\%$ disagreed with the item: *A man who has no taste for adventure is not very appealing to a woman.* Likewise, more than a half of the participants strongly agreed ($44.1\%$) or agreed ($38.1\%$) with the premise: *A man should get up to investigate if there is a strange noise in the house at night.* This tendency was shown regardless of the age of participants. Also, men indicated that raising a boy is different from raising a girl. They ($54.8\%$) agreed that a boy should prefer playing with cars instead of playing with dolls.
On the other hand, adherence to traditional gender roles decreases when we explored behaviors related to household work that are traditionally considered part of feminine roles. Sixty-six percent of participants strongly disagreed with the item: Domestic work is women's work. Also, 44.8% of these men think that they could carry their wives' purses and this action will not challenge their masculinity. For these men, caring for their own physical appearance (47.9%) and asking for help to change a tire, for example, (39.7%) are not exclusively women's behavior.

Participants indicated that they agreed that men should express their feelings. They strongly disagreed (29.9%) or disagreed (30.8%) with the item: Nobody likes a man who cries in public. At the same time, these men strongly disagreed (37.8%) or disagreed (35.3%) when we asked their opinions regarding the statement: A man should never reveal his concerns to other persons and 27.8% strongly disagreed or disagreed (35.7%) with A man should not show how he is feeling. Twenty percent of participants agreed that: If a man is in pain, it is better for him to let people know than to keep it to himself, while 44.8% of participants disagreed that being a: Little down in the dumps is not a good reason for a man to act depressed. Forty-three percent strongly agreed and 29.6% agreed that: A man should kiss his father and A man can show affection to other men, respectively. Also, 24.2% indicated that they strongly disagreed and 28.3% disagreed with the statement A man should always be ready for sex.

Participants did not express a clear position regarding what society expects from men to prove their masculinity through their behavior nor about the role of being the main provider for the family. We found that for some items a similar percent of participants agreed or disagreed with them. For the premise: It is important for a man to take risks although he may be hurt, 22.4% strongly disagreed and 21.6% strongly agreed with the statement. Meanwhile, for the item: A man should always be the main provider in his family, 23.9% disagreed and 22.2% agreed. Basically, half agreed and half disagreed with the statement: Jobs as electrician and firefighter should be for men.

**DISCUSSION**

The objective of this research was to describe non-adherence behavior in a sample of men living with HIV in Puerto Rico. Adherence to treatment is a complex behavior that receives
Challenges to Antiretroviral Adherence

Impact from numerous psychological, sociological and biomedical realities (Chesney, Ickovics, Chambers, Gifford, Neidig, and Zwickl, 2000). Non-adherence behavior represented a common and serious problem for both the patient and the health care provider. In the management of chronic illnesses, patient non-adherence behavior frustrated care providers, had a negative impact on individual health and burdened society in terms of both adverse health outcomes and staggering economic costs (Simoni, Frick, and Huang, 2006).

In this study, the most frequent mode of transmission reported was sexual contact: heterosexual and men who have sex with men. The literature stated that people who use drugs have suboptimal levels of adherence (Hinkin, Barclay, Castellon, Levine, Durvalsula, Marion, et al., 2010; Kerr, Palepu, Barnes, Walsh, Hogg, and Montaner, 2004). These findings were consistent with the study of Negrón-Chaves et al. (2005) carried out in Puerto Rico. Also, consistent with the findings of Hinkin et al. (2010), our findings indicated that drug use was directly related with non-adherence behavior.

In terms of the psychiatric characteristics, in the present study, the participants did not show significant depression symptomatology. This result was consistent with the findings of Applebaum and his collaborators (2009), who found that depression was not a significant predictor of adherence. However, other studies found that depression is a predictor of adherence (Ammassari, 2004; Negrón-Chaves et al., 2005; Reich, Lounsbury, Zaid-Muhammad, and Rapkin, 2010). It is possible that the findings of this study reflect other characteristics endemic to this sample. Most of the participants reported living with HIV and having used the medication for more than six years. Today, HIV is seen as a manageable chronic condition and, further, it is understood that one can live with the disease using HAART. That awareness could help the person living with HIV to deal with the disease and, as a consequence, decrease depression symptomatology. In addition, the participants of this study were recruited from clinics where they have access to integrated medical and mental health care as a matter of routine.

Many of these men did not know their viral loads and CD4+ cell count, which could be a barrier to health care. In a study conducted in Puerto Rico, Andújar (2006) found that many of the participants in his study also did not know their status in terms of these biological markers. Viral loads and CD4+ cell count are important measures to assess the progression of the HIV, and they delineate the best therapy to manage the disease. Controlling for years of education, Kalichman, Benotsch, Suarez, Catz, Miller, and Rompa (2000) found that persons with lower health literacy were significantly less likely to have an undetectable HIV viral load and somewhat less likely to know their CD4+ cell count and viral load, and that lower health-literacy persons who knew their CD4+ cell count and viral load were less likely to understand their meanings. Poor health literacy creates barriers to fully understanding one’s health, illness and treatments. These results are surprising because we hoped that the more time the person has had living with the condition, the better they should have developed the necessary skills to manage the disease, ensuring adherence to the treatment. Our results could mean that the participants have, instead, more fatigue and tiredness after years of using the medication.

Some of the participants indicated that they did not take the pills on weekends because they wanted a break from the medication or because they wanted to go out to drink. Others reported that they forgot to take the medication when they changed their routines, like, for example, when staying at a friend’s house. Grimes (2002) indicated that, if using the medication interferes with daily routines, encompassed in the context of the person’s social...
life, then it can drive the person to stop taking his medication or do to take it at the wrong time.

The literature stated that inadequate adherence causes treatment failure (Paterson, 2000). We also found that participant’s medications were changed frequently. They reported up to 16 changes of their medications, changing one or more of the person’s HIV medications. We found inconsistent behavior with the use of the medication, which is a concern because these patients are at risk of developing health complications or drug resistance. Research shows that even modest or occasional non-adherence to HAART greatly diminished the benefits of treatment (Gonzalez et al., 2004). The omission of even a single dose could have consequences on treatment success. Among patients who adhered to between 80% and 90% of their HIV treatment doses, Paterson (2000) found that only 50% achieved viral loads below detectable limits.

In our study, we found that “forgetting” was the most frequent reason to skip the HIV treatment; this finding is consistent with what was found in other studies conducted with people living with HIV (Amassari, Antinori, Aloisi, Trotta, Murri, Bartoli, et al., 2004; Chesney et al., 2000; Kemppainen, Kin-Godwin, Reynolds, and Spencer, 2008; Negrón-Chaves et al., 2005). It is relevant because most of the participants have many years living with the condition, and the mean age of these men was 45 years. These results reflect the changing trend of the epidemic, where the populations living with HIV live longer, adding other variables (such as age and the development of other co-morbidities, among others) to the treatment of this population (Kissel, Pukay-Martin, and Bornstein, 2005). These factors should be considered in designing intervention plans or educational programs. Issues related to the impact of HIV infection at the central nervous system should be explored, as memory loss could be expected with age and mental deterioration.

In addition, we explored the relationship between social support and medication adherence. Research has documented the positive impact that social support has on people living with HIV (Chandra, Desai, and Ranjan, 2005; Carrobles et al., 2003, Toro-Alfonso and Varas-Díaz, 2004; Vera-Pérez and Estrada-Aguilera, 2004). Negrón-Chaves et al. (2005) found a statistically significant relationship between family social support and the level of compliance with the medications. In our study, non-adherent participants perceived lower levels of social support. This result is similar to those found by Cardarelli et al. (2008) and Gonzalez et al. (2004), who found that non-adherent participants showed lower scores in terms of social support perception.

Many of our participants were living alone, and they reported that their primary sources of support were their siblings. For the Latino culture, having support from family is very important. Fekete, Antoni, López, Durán, Penedo, Bandiera, et al. (2009) indicated that Latino men who had disclosed their HIV status to their mothers were receiving low levels of HIV specific family support experienced poorer disease status. Our findings showed that lack of social support contributes to not having adequate adherence behavior. Some participants indicated that they did not take their medications because they did not have transportation to get to their medical appointments or to the pharmacies to refill their prescriptions.

Social support, especially from family, has been demonstrated to be a significant factor in enhancing adherence (Carrobles et al., 2003; Negrón-Chaves et al., 2005; Remien, 2002; Vera-Pérez and Estrada-Aguilera, 2004). It is necessary for patients to understand the need to incorporate family into their life planning to manage their illnesses. Family-oriented
interventions are widely practiced with patients who have chronic mental illness, drug abuse, mental retardation and cancer, among others (Remien, 2002). Relatives should be facilitators of change in adherence behavior, and they could motivate patients to enhance the use of treatment. The size and availability of social and family support, and the satisfaction with it, are significantly associated with health status and perceived quality of life for people living with HIV (Villa and Vinaccia, 2006).

Social support provides the individual with a sense of stability, predictability and control that leads him to feel better and to have a more positive perception of his environment (Villa and Vinaccia, 2006). Most adaptive tasks of managing a chronic disease require help from others, including emotional sustenance and practical aid (Stanton et al., 2007). Social support can help recipients to use effective coping strategies by offering better understanding of the problem and increasing the motivation to take action. The perception of having support encourages people to develop self-health care behaviors, as well to make a better use of their own personal and social resources.

Some studies have clearly underscored that beliefs about the illness are associated with adherence levels, management strategies and self-management of the disease (Cabassa and Lagomasino, 2008; Hagger and Orbell, 2003, Petrie et al., 2007). Medication adherence is influenced by illness and treatment beliefs, and treatment beliefs are influenced by experienced symptoms and adverse medication side effects.

In this study, many of the participants have been in HAART a long time, and exhaustion could be a reason for not using medication in a proper manner. The complicated itineraries of the medication, disease symptoms and medication side effects are factors that could cause men to stop taking the pills. Beliefs about HAART efficacy could be changing as a result of years using the treatments and also with the educational levels. Health care providers must examine how much knowledge and the misconceptions that patients have after years living with HIV, in order to develop interventions that engage the patients with their treatments, taking into account educational and informational levels.

Our findings indicate that these men moderately adhere to traditional gender roles. They agree with traditional roles in areas such as how a boy or a girl should be raised and the necessity of demonstrating power. They believe their roles are influenced by the rules required in the socio-cultural context. On the other hand, participants also agreed that men can show their own emotions, do household work and care for their own physical appearances. These results seem to demonstrate that these men attempt to cope with their own realities while they manage the demands of the hegemonic masculinity.

People living with HIV have to deal with a complex treatment, disease symptoms, medication side effects and stigmatization, which can lead them to experiencing marginalization. To handle this situation, these men need to reformulate their understanding of hegemonic masculinity in order to make sense of their own circumstances. In a study conducted on men with severe arthritis, the author found that the greatest impact of the disease (in terms of pain, fatigue, and ability to maintain employment and to participate socially) on the men’s lives was on their sense of self and masculinity (Gibbs, 2005).

Men with a chronic illness may experience a crisis, not only in terms of their health status but also on their sense of their own masculinity and their place in the gender order and in gender relations (Schofield et al., 2000). The impact of suffering an illness may limit men’s capacity to work, socialize and maintain their role in relation to partners and friends. For this reason, these men may show a new view of their masculinity, which was reflected in the
findings when participants did not express a clear position regarding the statement related to demonstrating their masculinity. As Gibbs (2005) indicated:

 [...] the impact of severe chronic illness can undermine a man's sense of his own masculinity in reference to the dominant social construction of masculinity, resulting in an adjustment of men's sense of their own self and their own masculinity, their place in the gender order and their experience of gender relations. This resulted in a rejection or reformulation of hegemonic masculinity to accommodate the need to access self-management services (p. 297).

They redefine their concept of their own masculinity as a mechanism to cope with and manage their disease. For these men, the medication could represent a limitation for their daily activities.

Limitations

Our study was subject to several limitations. The sample of this study was recruited by availability (a convenience sample) in clinics that provide specialized services to persons living with HIV and, as a consequence, the sample is not representative of all people living with HIV in Puerto Rico and, instead, presents homogeneous characteristics. Most of these clinics operate under the same model and offer similar services; they also uniformly have a team of multidisciplinary health care professionals.

More specifically, the sample was recruited while people sought medical care, and most of the participants were living in metropolitan areas—another reason why we cannot make inferences from these results. Also, this is a cross-sectional study that does not allow us to follow up on how the adherence behavior varies over time. A longitudinal study would permit a broader examination of the adherence behavior, how health beliefs change over time and a review of daily activities in persons living with HIV related to the use of the medication.

CONCLUSION

Some variables, such as culture and ethnicity, gender, social resources and personal resources, personality attributes and coping appraisal processes, have been identified as determinants of adjustment to chronic illness (Tedlie-Moskowitz and Wrubel, 2005). Men’s health has emerged as an important public concern that may require new kinds of healthcare interventions and increased resources (Schofield et al., 2000). Our study has several implications. Understanding the behavior of non-adherent men is important because personal disposition, individual events and socio-cultural influences likely combine to shape how the person perceives and responds to his treatment.

Men’s health is affected by masculinity, which requires that health care professionals be aware of the meaning of masculinity and its relation with the quality of life that results from constantly using medications. Spending many years using medication can lead patients to develop misconceptions, which might lead to them to avoid treatment or to do it in an
incorrect manner. For this reason, patients should receive informational support even when they do not request it.

Many clinical implications can be derived from this study. Health care providers must recognize that patient knowledge about the disease is not enough to maintain adherence behaviors. Patients who have been living with HIV for a long time might suffer exhaustion after years using medication. Health care providers must recognize that personal beliefs may influence patient’s quality of life and adherence behavior. Open and ongoing communication is necessary between the clinic's staff and persons living with HIV. Our results suggest that, when a person living with HIV has been using treatments for a long time, motivating him is essential in an effort to endorse and reinforce the maintenance and use of medication in a proper manner. Health care provider’s interventions should include an evaluation of the different aspects that are involved in medication adherence and the management of a chronic stigmatized disease.

REFERENCES


