The Role of Social Support on Health-Related Practices of HIV-Discordant Heterosexual Couples.^{1,2}

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Abstract

Social support has been established as an important factor for health maintenance and general well-being. In Puerto Rico, research has neglected to explore this subject among HIV-Discordant couples. Our study aimed to explore the perceived role of social support within HIV-Discordant couples, specifically its perceived impact on safer sexual practices and adherence to treatment. We implemented an exploratory and transversal qualitative design, and we carried out in-depth interviews with 20 heterosexual HIV-Discordant couples (n=40). Results highlight the important role that social support plays on adherence to treatment and condom use while also documenting the challenges faced in providing and receiving that support. Recommendations for future research and intervention development are provided.

Keywords: social support, HIV-Discordant couples, HIV/AIDS

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Resumen

El apoyo social ha sido un factor importante para el mantenimiento de la salud y el bienestar en general. En Puerto Rico, las investigaciones no suelen enfatizar en la exploración de este tema entre las parejas VIH discordantes. A través de un estudio exploratorio y un diseño cualitativo transversal examinamos la percepción de apoyo social en 20 parejas VIH discordantes (n=40), específicamente el impacto percibido en las prácticas sexuales más seguras y la adherencia al tratamiento antiretroviral. Los resultados obtenidos señalan la importancia del apoyo social en la adherencia al tratamiento y el uso del condón. Además, documentan los retos que enfrentan las parejas en proveer y recibir ese apoyo. Identificamos recomendaciones para futuros estudios e intervenciones.

Palabras clave: apoyo social, parejas VIH discordantes, VIH/SIDA

Racial and ethnic minorities continue to be disproportionately affected by the HIV epidemic in the United States. Latinos, including Puerto Ricans, comprise 16% of the population but accounted for 20% of the new diagnoses in 2009 (CDC, 2011a). Puerto Rico is one of the most affected areas among the US territories with more than 32,000 reported cases (Puerto Rico AIDS Surveillance Report, 2011). HIV heterosexual transmission continues to grow exponentially among Puerto Ricans encompassing more than 40% of all reported cases. HIV-Discordant couples (HDC), where partners have different HIV status, have been recognized as a priority for HIV prevention in the US and developing countries (Joint United Nations Programme on HIV/AIDS, 2009). HDC need urgent attention in order to prevent the infection of the negative partner and promote the infected partner's adherence to highly active antiretroviral therapy (HAART). HAART is a standard treatment for people with HIV/AIDS (PWHA) that consists of a combination of at least three drugs that suppress HIV replication (WHO, 2012).

In the United States, HIV heterosexual gender inclusive interventions have been sparse, as they are primarily directed towards women (Higgins, Hoffman & Dworkin, 2010; Pérez-Jiménez, Seal & Serrano-García 2009). It is recommended to include both members of the couple in the interventions to achieve higher effectiveness (Pérez-Jiménez, Seal & Serrano-García, 2009), particularly the heterosexual men who often are excluded from studies and interventions (Higgins, Hoffman & Dworkin, 2010; Herbst et al., 2007).

Focusing on HDC is an innovative way of tackling adherence to HAART and safer sexual practices. Various HIV-Discordant couple preventive interventions have proven to be effective, (Desgrées-du-Loû & Orne-Gliemann, 2008), however most of these studies have been conducted outside the United States (El-Bassel et al., 2003). Similarly, in Puerto Rico there are only few HIV studies and interventions that concentrate on couple dynamics (Pérez-Jiménez & Orengo-Aguayo, 2011; Orengo-Aguayo & Pérez-Jiménez, 2009) while the majority of HIV studies and prevention efforts continue to concentrate on the individual level.

There are important factors within the dynamics of HDC that must be addressed in HIV primary and secondary prevention strategies. In this article, we address the role of social support in adherence to HAART and condom use among Puerto Rican HDC in order to contribute to a sensitive approach for promoting healthy practices within couples.

Adherence to Treatment and Condom Use in HIV-Discordant Couples

PWHA deal with the stress associated with a life-threatening illness while simultaneously coping with the challenges that their HIV status imposes on their relationships (VanDevanter, Thacker, Stuart; Bass, & Arnold, 1999). The impact of HIV on relationships has been documented in different dimensions of everyday life such as perceived stigma, status disclosure, and sexual practices (Rispel, Metcalf, Moody & Cloete, 2002).

Interpersonal dynamics have not been well explored among HIV-Discordant couples (Stevens & Galvao, 2007). Research has shown that it is important to take into consideration different aspects of relationships between men and women (e.g. communication, *machismo* and violence) because they allow for shaping their health related behaviors such as condom use and adherence to treatment (Manfrin-Ledet & Porche, 2003). It is critical to address condom use and adherence to treatment issues in the context of HIV-Discordant couples because both are important to overall public health. Partial or poor HAART adherence can lead to a rapid viral replication and the development of mutant viral strains that are resistant to available antiretroviral drugs (Castro, 2005), which is in turn worsened when they engage in unsafe sexual practices.

Adherence to treatment

Adherence to treatment is a significant public health problem, particularly among persons living with chronic diseases (Woods & et al., 2009). Although HAART represents great progress in the fight against HIV/AIDS, one of the most important challenges facing this epidemic is adherence to treatment. Research based on adherence to treatment shows that close to 50% of participants in clinical trials with chronic diseases do not adhere to treatment (Osterberg & Blaschke, 2005). A meta-analysis of 59 studies conducted in the US reported that only 55% of patients demonstrated high levels of HAART adherence (Mills et al., 2006). Other studies have shown that up to 84% of participants miss medication doses (Dunbar et al., 2003; Erlen et al., 2002; López, Jones, Villar-Loubert, Arheart & Weiss, 2010). These findings are of concern because it is widely known that adherence to HAART is a strong predictor of the progression to AIDS and death (Machtinger & Bangsberg, 2006).

Several factors are associated with non-adherence including: alcohol and drug abuse (Murphy, Greenwell & Hoffman, 2002), difficulty of medication regimens (Roberts & Mann, 2000), fear of side effects (Dunbar et al., 2003), depression (Starace et al., 2002), and lack of social support and self-efficacy (Pequegnat et al., 2012). A study to document non-adherence behavior in a sample of HIV positive men in Puerto Rico revealed that most of them perceived low levels of social support (Nieves-Lugo & Toro-Alfonso, 2012). In another study with Puerto Ricans, Robbins and colleagues (2012) showed the importance of understanding the role of an individual's social-cultural experience because it can help illustrate why PWHA have difficulties achieving optimal HAART adherence and how HAART adherence interventions can be improved. Precisely, social support, as part of the social-cultural experience, has been documented to have the effect of enhancing adherence to HAART (Nieves-Lugo & Toro-Alfonso, 2012; Rodríguez Madera & Varas Díaz, 2012). According to some researchers, the Benefits of social support among PWHA are: a positive impact on mood, improvement of quality

of life and, feelings of empowerment (Carrobles, Remor & Rodríguez-Alzamora, 2003; Toro-Alfonso & Varas-Díaz, 2004).

Research related to HIV status among couples and its impact on adherence to HAART identified that barriers in adherence are related to psychological factors such as: negative perception of the relationship, absence of emotional support, and having an unsupportive partner (Murphy, Greenwell & Hoffman, 2002; Wagner, Remien, Carballo-Dieguez & Dolezal, 2002). In a study with 42 HIV-Discordant couples, Remien and Stirrat (2002) found that there was a relationship between adherence to HAART and safer sex practices. In addition, poor adherence was significantly associated with increased manifestations of unprotected anal/vaginal sex with the primary partner.

Adherence to condom use

Studies have found that HIV-discordance imposes pressure and feelings of alienation within relationships (Stevens & Galvao, 2007). Fear of HIV transmission, shifts in emotional intimacy, barriers to communication, dilemmas regarding how HIV will impact their lives, and lack of reproductive alternatives have been identified as commonly experienced issues for HDC (Beckerman, 2002; Grinstead, Gregorich, Choi & Coates, 2001). Other challenges include rejection, abandonment, HIV status disclosure, financial planning, and practicing safer sex (Persson, 2008).

Engaging in safer sexual practices is not easy, particularly when those practices are related to condom use. Factors such as motivation and positive attitudes towards condoms have been documented among Puerto Ricans as important variables to address when promoting safer sex (Pérez-Jiménez, Serrano-García & Escabí Montalvo, 2007). Negative attitudes towards condom use, which lead to risky sexual behaviors, can be related to social norms that govern heterosexual relationships. In the context of couples, abstinence seems to be an impossible and unreasonable demand, and condom use is complicated by social factors that link their use to perceptions of unfaithfulness (Hirsch et al., 2007). For example, research has shown that women with HIV/AIDS in HDC reported resistance from their partners to the idea of using condoms, which in turn exacerbates their feelings of guilt and concern over potential infection (Stevens & Galvao, 2007).

Even more concerning is the growing evidence indicating that the proliferation of HIV treatment options over the past decade may have decreased individuals' concerns about HIV transmission (Stevens & Galvao, 2007). Findings from studies in the US suggest that PWHA engage in more unprotected sexual intercourse after they are on HAART (Buchacz, et al., 2001; Wilson, et al., 2004). Researchers have found that PWHA in couple relationships frequently practice unprotected sexual intercourse with their partners, independent of their HIV status (Bova & Durante, 2003; Weinhardt, et al., 2004). Still, gaps remain in specific knowledge about the factors that impede or facilitate their capacity to reduce risky sexual behaviors and adopt healthy strategies within the couple (Stevens & Galvao, 2007).

Social Support: A Determinant of Health on HDC

Social determinants such as economic and social conditions influence the health of people and communities (Commission on Social Determinants of Health, 2008). These conditions are shaped by people's economic sources, which are influenced by policy choices. Social support

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has been identified as a social determinant of health (CDC, 2011b; WHO, 2003). Social support is related to the exchange of social-emotional, instrumental, and recreational resources in the interactions within families, partner relationships, friends, coworkers, neighbors, church and/or religion, and health professionals (Bernal, Maldonado-Molina, & Scharrón del Río, 2003). Although operational definitions of social support vary, there is a growing consensus that increased general social support is often a protective factor in coping with challenges imposed by HIV particularly due to its positive effect on diminishing depression-related illness (Aderson et al., 2009; Johnson et al., 2001).

According to Darbes et al. (2011), in the realm of HIV, examinations of social support have frequently focused on coping with being HIV positive or having AIDS or the progression of the disease. As an important determinant of health, social support has been strongly associated with decreased AIDS mortality (Young, De Geest, Sipirig, Flepp, & Rickenback, et al., 2004). In the context of HDC, social support from partners has been associated with less progression to AIDS in the infected partner (National Collaborating Centre for Infectious Disease, 2010). However, the literature on HIV/AIDS has focused on the HIV positive individual rather than the HIV negative, for whom it may also be difficult to find or receive support (McDowell, 2008).

Good social support levels contribute to a better quality of life, help provide an adequate understanding of the illness, and offer mental and physical health benefits (Olapegba, 2005), including adherence to treatment (Aderson et al., 2009; DiMatteo, 2004; Uchino, 2006, 2009; Wrubel, Stumbo & Johnson, 2010). Although perceived social support can be beneficial to the patience's adherence to treatment (Power et al., 2003), its effects may vary depending on a wide range of factors (DiMatteo, 2004). As we previously identified, studies with HDC have evidenced that social support can facilitate the maintenance of adherence to HAART (Power et al., 2003; Remien et al., 2005). The association of social support with sexual risk behaviors has been less conclusive due to contradicting reports from various research efforts. Some reports link social support with increased sexual risk behaviors (Miller & Cole, 1998), while others show decreased risk (Darbes, 2011). It seems that social support might be a reliable predictor of psychological rather than behavioral outcomes (Darbes, 2011).

In general, prevention targeting HDC has emphasized the importance of: (a) counseling and testing, (b) group-based interventions which provide information, HIV risk reduction strategies, and development of personal skills, and (c) provision of a supportive environment through stigma reduction (USAID & AIDSTAR-One, 2010). In Puerto Rico, the few HDC interventions that have occurred have not been systematically evaluated, and more preliminary information on the role of social support is needed for its evaluation in future interventions (Pérez-Jiménez & Orengo-Aguayo, 2011). Considering the lack of research addressing the role of social support on secondary prevention among Puerto Rican HDC and the intertwined role of adherence to HAART and condom use, relationship experiences within these couples need systematic attention. Understanding the dynamics of such relationships and how members of the couple interpret them can yield important information that will help develop interventions for HDC in Puerto Rico. In light of the challenges posed by the HIV/AIDS epidemic in Puerto Rican HDC, our study aimed to explore the perceived role of social support within the HDC, specifically its perceived impact on safer sexual practices and adherence to treatment.

Method

Participants

In order to achieve the aims of the study, we used an exploratory and transversal qualitative design. We carried out in-depth interviews with 20 heterosexual HDC (n=40). The dyads were balanced by the gender of the person with HIV in order to gather information from couples where women and men were HIV positive.

The sample for our study included 40 participants (20 couples) that engaged in open question interviews. All participants met the following inclusion criteria: (a) being Puerto Rican living on the Island at the time of the study; (b) older than 21 years of age; (c) be an HIV positive person with an HIV negative partner; (d) being under HAART treatment or having partner who is; and (e) being in an heterosexual relationship during the previous six months in which both partners know about each other's HIV status. Furthermore, both members of the couple needed to be willing to participate in the open question interviews. We implemented these inclusion criteria in order to ensure that the findings of the study were relevant to Puerto Rican HDC.

All participants were residents of the San Juan metropolitan area with an average age of 44 years. Most (73%, n=29) had not completed high school, and 63% (n=25) were unemployed at the moment of the study. Seventy percent (n=28) lived with their partners at the time of the interview and 68% (n=27) identified their partners as the primary source of social support.

Instruments

Participants completed several measures. These included the following: (a) a screening form that addressed all the inclusion criteria described above; (b) an informed consent form detailing the study objectives; and (c) a demographic data questionnaire. We developed three semi-structured interview guides, which served to maintain a minimum level of uniformity across participants' interviews. These guides included: two versions (for the HIV positive person and the HIV negative partner respectively) and a third one for the couple interviews. The interview guides addressed issues related to overall experiences with HIV, social support, perceived impact of HIV/AIDS on couple dynamics, sexual practices and adherence to treatment. Guides for HIV negative participants included questions about their perception regarding partners' adherence to treatment. The interview guide for couples included questions that were asked to both partners simultaneously, placing emphasis on the couples' perspective. For content validity, a panel of five experts in HIV related research reviewed the interview guides. We also conducted pilot interviews with two couples to test their understanding of the questions in the developed forms.

Procedure

We recruited the participants from Puerto Rico's largest facility complex for treating PWHA. This facility comprises eight government-operated centers that provide health related services to approximately 10,000 PWHA in Puerto Rico. We met with the facility administrators prior to participants' recruitment to fully explain the purpose of the study. A recruiter from the facility identified the potential participants according to the inclusion criteria and made the initial approach. In this initial approach, the recruiter familiarized the potential participants with the

nature of the study. If the potential participants were interested in being part of the study, the recruiter gathered their contact information. Afterwards, a member of the research team invited them to participate and administered the screening form to ensure that individuals complied with the inclusion criteria. We informed participants on the site if they were eligible to participate. If the partner was present, we gave him/her the screening form immediately; otherwise, we provided the participant with information about the study and scheduled a meeting in which he/she could bring their partner in order to carry out the invitation. We provided the participants with our phone numbers in case they had doubts when explaining the study to the partner or needed to change the scheduled meeting. We gathered consent individually to avoid coercion by one member of the couple. Only two of the recruited couples decided not to participate in the study.

We conducted the interviews in private rooms. Once we interviewed the participants individually, we conducted the couple interview. Interviews were audio recorded. Each one took approximately one hour.

Data analysis

To ensure the fidelity of our analysis, we implemented a transcription process (Poland, 2002). We supervised the transcription process in the following manner. First, the investigators trained research assistants on how to appropriately transcribe an audio interview verbatim, and then the research assistants carried out the transcriptions. When the transcriptions were completed, the research team double-checked for inconsistencies while listening to the audio recording. Finally, the entire team met and corrected all errors in the transcriptions. Once the research team completed this process for each audio recording, we began the data analysis process.

We met on a weekly basis to identify themes or patterns that emerged from the content of the transcriptions. We developed a running list of themes to keep as a master list for the content analysis. Once we identified the general themes for all the interviews (e.g. instrumental and emotional social support, challenges to adherence to treatment and condom use), we conducted a literature review to evidence them in the transcriptions, holding weekly meetings to ensure the texts we found were appropriate to the subject matter (Phillips & Ardí, 2002). This consensus-based dispute resolution procedure generates an inter-rater reliability of 100% for such analyses (Miller, 2001). This ensures that the analysts agree on the final interpretation of the coded passages and avoids the inclusion of verbalizations that are unclear in their phrasing or overall meaning. We used the qualitative analysis computer software Nudist Nvivo (V.8.) to facilitate the text selection and coding process. To summarize, we followed several standard procedures to ensure the trustworthiness of our collected data (Lincoln & Guba, 1985; Schwandt, 2001). These included: (a) supervising the overall transcription process of the audio recorded interviews, (b) holding meetings to discuss the quality of these transcriptions, and (c) establishing group discussions throughout the data collection and analysis process so that our team members could discuss concerns and findings. We presented the results from this process in the following section. Note that the quotes presented here were translated from Spanish to English.

Results

Findings from this study highlight issues of importance regarding social support between HDC that need to be addressed in preventive initiatives in the Puerto Rican context. We present four categories that highlight the challenges faced by HDC and the potential role of social support for their overall health. These include the following: (1) challenges in adherence to treatment, (2) social support and adherence to treatment, (3) challenges in condom use, and (4) social support and condom use.

Challenges in adherence to treatment

According to participants, difficulties with adherence to treatment were associated with oversights, the complexity of the regimes, side effects and depression. Forty percent of participants (n=8) reported having trouble with adherence, and of those, the majority were females (63%, n=5). Partners also described such difficulties. Some examples of the difficulties that the HIV positive participants mentioned in the interviews are:

<u>Oversights</u> - "I forget because I usually get involved in other activities. Time goes by rapidly" (HIV Positive Woman).

<u>Complexity of regimes</u> - "It's difficult to take pills every day... one gets tired of thinking that this will be for the rest of my life. When having breakfast, I start looking at the pillbox... and I say Hell" (HIV Positive Woman).

In addition, some HIV negative participants also mentioned their partners' difficulties to adherence to the treatment.

<u>Drug side effects</u> - "It's not easy and she [HIV positive partner] gets indisposed with meds. Side effects affect her really bad" (HIV Negative Man).

<u>Depression</u> - "It's like laziness. She doesn't want to deal with medicines, even when I try to make things easier for her" (HIV Negative Man).

Even when facing the challenge of adherence to treatment, partners provide a crucial source of support for the task. Many of the HIV positive participants identified their partners as supportive in having a good adherence to treatment through consistent follow-up and reminders.

Social support and adherence to treatment

Most of the participants (68%, n=27) considered their partners as the main source of social support. In general, we found that HIV positive men reported receiving more emotional support from their partners than HIV positive women. In contrast, HIV positive women verbalized more instances of instrumental support (i.e. HIV related specific physical tasks) for adherence to treatment than HIV positive men.

Participants' narratives on emotional support specifically alluded to their role in improving their partner's self-esteem. Strategies such as giving compliments, offering advice on how to direct their focus away from their HIV status, demonstrate their reliability by always

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being around their HIV positive partner, and considering HIV as any other illness were reported as beneficial. Some specific examples of emotional support include:

<u>Giving compliments</u> - "I am always looking out for her... you have to provide them [PWHA] self-esteem. Persons with HIV need to receive a lot of support. If not, they become depressed. I cannot let that happen..." (HIV Negative Man).

<u>Direct their focus away from their partner's HIV status</u> - "He is always there... He sits and talks to people [in the clinical scenario] and they think that he is the sick one... not me" (HIV Positive Woman).

"When he does not feel well emotionally, I try to talk to him, encourage him, so he can get out of the depression. I usually motivate him and remove those negative thoughts" (HIV Negative woman).

"I try not to make him feel bad . . . I try to make him feel as happy as possible. He is sick... In addition, am I going to tell him that he is sick?" (HIV Negative woman).

<u>Demonstrate reliability</u> - "I am her nurse. More or less... I act as her nurse. I follow her every step of the way... I never leave her alone, and she is well. The virus load is very low" (HIV Negative Man).

Although we considered emotional support as an important factor within the relationship dynamics and HIV positive partners' well-being, based in the participants' responses we could not identify it as an appropriate strategy for achieving adherence to treatment. Contrary, we identified in the data collected that instrumental support was an appropriate strategy. In the interviews, participants reported different mechanisms for facilitating adherence among their partners; from constant reminders to being familiarized with the medicines protocol in order to follow-up the process. Some examples of specific instrumental support include:

<u>Constant reminders</u> - "She is always taking care of me... She reminds me, "Did you bring your pills?" I am very happy with her support. Definitively it is making a difference" (HIV Positive man).

"I am used to them [taking medicines]. I think of them [pills] as if they were vitamins. If I want to be healthy, I have to take my medicine. Anyways, he does his part... always asks me: Did you take your pills?" (HIV Positive woman).

"I go with her to the doctor's appointments. I remind her every day to take her meds and I give my support in the house" (HIV Negative man).

"I have to be involved, because I have to remind her of the pills and doctors' appointments. Sometimes if I can't go with her to the doctor, she doesn't go by herself. In addition, she doesn't have anyone else to help her with her daughter." (HIV Negative man).

<u>Being familiarized with the medicines protocol</u> - "He hides the medicines behind his back, puts them in his hands, kisses them, and then when giving them to me says, "with faith." It makes me feel good because someone loves me and takes care of me." (HIV Positive woman). I have not stopped taking my medicines because he is always taking care of me. If it were only me, I would forget [to take the pills]. He is always aware, and at 9:00 AM before leaving for work, he gives me the pills... and at 9:00 PM. (HIV Positive woman).

Other participants reported contributing economically for purchasing medicines, while others were always following up with pill availability. One participant mentioned:

<u>Purchasing medicines and pill availability</u> - "I know that every three months I have to get the refills . . . I go, stand in the queue and get them. I go and get the medication before it is finished" (HIV Negative man).

Evidently social support from partners seems to be an important factor for those who identified having adherence to HAART. Although adherence was clearly interpreted as part of a healthy lifestyle and a preventive approach, condom use to avoid HIV infection seemed more of a challenge and an area where support in the couple was less clear.

Challenges in condom use

Half of the participants reported not using condoms during sexual activity with their partners. Some of HIV negative men that used condoms during the sexual activity, mentioned to dislike them. They stated that they always use condoms because they have to:

"There are a lot of things that you can't do. I don't like to use condoms... but I use them always. Every time that we have sex, I use condoms and it bothers me because I don't like them" (HIV Negative man).

"If there are no condoms, we don't have sex. She says that condoms bother her... that it's not the same. I understand her because I am allergic to condoms [laughs out loud]. Mentally allergic! Of course it's not the same, no, no, no. But I have to deal with that" (HIV Negative man).

Most of the participants in our study (90%, n=36) knew each other after the HIV diagnosis of one member of the couple; however, some of them had unprotected sexual intercourse before sharing their HIV status to their partners. The consequences of these actions encompass psychological anxiety and guilt, as described by some participants:

<u>Psychological anxiety</u> - "For me it was a shock... thinking that he did not tell me anything about his condition. Wow, you can be infected if you are not protected! During that time that we were together, without me knowing that fact, we had sex. I wanted to kill him because I believed that I was also going to be sick. After that we used condoms" (HIV Negative woman).

"I have penetrated her on several occasions without condoms because she agreed with it. Then I used them [condoms]... I am scared for her. I told her that she must go to the doctor.

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Sometimes I don't use her [have sex with her] because I am having sex with other people. It is with people that she knows" (HIV Positive man)

<u>Guilt</u> – "I felt bad and guilty because I made her suffer. I didn't tell her [HIV status] at the beginning. I was also scared because I thought that maybe she could have it too. When I told her, she started to cry. Later she accepted me because everything in life is possible if there is love" (HIV Positive man).

After HIV disclosure, some participants described not using condoms in the sexual intercourse. Both members of the couples agree with it. Some HIV positive partners gave some reasons for not using condoms such as being tired of using condoms and because condoms do not fit properly.

<u>Tired of using condoms</u> - "We don't use condoms because we were tired of them, but he has his labs results every three months" (HIV Positive woman).

<u>Condoms do not fit properly</u> - "Poor thing! He doesn't use them because they slip off. Can you imagine? It is OK with me" (HIV Positive woman).

Certainly, condom use is still a major challenge for HIV prevention. In addition to other social variables, lack of social support for condom use plays an important role in risk behaviors.

Social support and condom use

Half of the participants reported using condoms during sexual intercourse, and they identified their use as a manifestation of support to their partners.

<u>Condom use as a support</u> - Well, I wish I did not need to be protected [with condoms] and use it [the penis] as intended by God. He created humans to have intercourse with nothing done by man... but this disease is transmitted to the partner if one is not protected. If there were no condoms... you can imagine that you will infect your partner. We are lucky that we have condoms to avoid placing your partner at risk (HIV Positive man).

Yes, we use condoms because we have to protect me. At the beginning I was scared because he was sick. Then he explained to me: "Hey, babe... this is how we are going to do it. If we use condoms you will not be infected". So he always uses protection, and I have them [condoms] also with me... just in case (HIV Negative woman).

On the contrary, some participants perceived condoms as reminder of their condition, attributing negative emotions (e.g. fear and disgust). The following quotes evidence the diverse meanings ascribed to condom use. In some cases not using condoms was indirectly considered a demonstration of emotional support to the HIV positive partner.

<u>Not using condoms as support</u> - "I worry about his HIV conversion... but when he does not use condom, he makes me feel desired" (HIV Positive woman).

"[Not using condoms makes her feel...] that he loves me, and desires me. That he does not fear me..." (HIV Positive woman).

Discussion

Adherence to treatment is of vital importance for PWHA because it can foster healthier living. Still, even while medication regimens have become simpler in recent years, complete adherence can be challenging (Toro-Alfonso, Andújar-Bello, Amico, & Fisher, 2002). In addition, PWHA present difficulties in achieved safer sexual practices. Condom use among heterosexual couples in Puerto Rico has multiple obstacles that include women's lack of self-efficacy in negotiating its use with partners and religious influences over what is "good" and "bad" sex (Rodríguez Madera & Marqués Reyes, 2006). Research in Puerto Rico has evidenced that women face serious difficulties negotiating condom use, particularly in long standing relationships (Ortiz-Torres, Serrano-García, & Torres-Burgos, 2000). In addition, there is evidence that men in general, have negative attitudes toward condoms use (Pérez-Jiménez, Serrano-García, & Escabí Montalvo, 2007). This study documented these challenges are evidenced in HDC dynamics and their adherence to healthier lifestyles. Even though it is expected that HDC have to have, after HIV disclosure, safer sexual practices and higher adherence to treatment, participants in the study mentioned challenges that prevent them for achieving it.

Social support plays an important role in the HDC dynamics. Our results echo findings from an extensive literature on the positive role of social support on overall health. This becomes crucially important for couples that face chronic diseases such as HIV. Social support can be a key aspect for both partners' health. In the study, most participants indicated that their partners where their main source of social support. This echoes previous studies carried out with HDC in Puerto Rico (Rodríguez Madera & Marqués Reyes, 2006). As in other studies, our participants identified the role of the HIV negative partner as beneficial for the health of the person in the couple living with HIV (Shandor-Miles et al., 2010).

Among different kinds of social support that have been identified in the scientific literature (i.e. emotional, instrumental, informational, recreational), we found that most participants' verbalizations were related to emotional and instrumental support. Emotional support is crucial for the success of partner relationships and for the appropriate management of a chronic illness (Checton, Green, Magsamen-Conrad & Venetis, 2012). It is the most commonly recognized form of social support and includes: empathy, concern, caring, love, and trust (House 1981). However, instrumental support is the most concrete, direct form of social support, encompassing help in the form of money, time, in-kind assistance and other explicit interventions on the person's behalf (House, 1981). Although this seems specific enough, a detailed analysis of the findings suggest several complexities when examining the way social support impacts health practices. One such complexity is the different roles that social support can have for adherence to treatment and condom use. A detailed examination of the findings suggests that social support was perceived as more influential on issues related to adherence to treatment than condom use. Both members of the couple describe how social support provided by the HIV negative partner was useful in adherence to the regimen. Simple tasks such as reminding them to take pills and providing a positive outlook on life were described as motivators to stay adherent. This was less clear when social support was mentioned in light of condom use. Even when participants described feeling supported for condom use, it was suggested that frequent condom use was a difficult task to achieve. Some participants expressed their dislike for condom use, even when they always used them to avoid HIV seroconversion. Meanwhile, not using condoms was described as a sign of love and desire.

Our qualitative findings suggest that even though members of the couple understand the positive effect of social support on adherence to treatment and condom use, the behavioral effects of that support were not always manifested (i.e. consistent condom use). This shows the difficulties reported in the scientific literature on condom use in general (e.g. heterosexual women's lack of self-efficacy in negotiating condom use, religious discourses on sexual behaviors, men's bad attitudes towards condom use).

Participants' verbalizations also shed light on the difficulties adhering to treatment that vary with gender. For example, women in general verbalized more problems adhering to treatment than men. On the other hand, HIV positive men reported receiving more emotional support than women. This difference may be attributed to the differential gender roles that are ascribed to women and men in Latino culture. In general, and this is also evident in Puerto Rican culture, Latina women are expected to be caretakers of their family members and their husbands. This is an important issue to address in future research since the role of social support on overall health may be influenced by PWHA adherence to traditional gender roles.

Findings from this study suggest the need to continue studying the role of social support on overall health among HDC in Puerto Rico. Specifically future studies need to address, from a quantitative perspective, the role of social support on health variables within members of the HDC. Furthermore, these studies need to address cultural variables that may influence that relationship (i.e. gender roles, religious discourses).

Although the qualitative nature of our study and the small size of the sample limit our ability to provide specific intervention guidelines for these couples, some recommendations can be stipulated. Most HIV prevention interventions at the primary and secondary levels in Puerto Rico have been implemented with individuals. Although this is crucial, interventions have assumed that health related practices are solely based on individual behaviors. Currently, most researchers would agree that contextual variables are also important for HIV prevention interventions (Grossman et al., 2011; Herbst et al., 2007). Couple dynamics is a contextual variable that needs to be addressed when aiming to reduce new HIV infections or adherence to treatment among those already affected. HIV prevention efforts in Puerto Rico need to take into consideration that individuals living with the disease engage in long-term relationships with HIV negative partners. Although some might suggest, based on stigmatizing attitudes, that PWHA should avoid having long-term relationships, the reality for individuals that are living longer is quite different. Therefore, interventions need to be tailored for this population in particular or adapted from those that have already been developed and tested in the United States.

References

- Aderson, M., Elam, G., Solarin, I., Gerver, S., Fenton, K., & Easterbrook, P. (2009). Coping With HIV: Caribbean People in the United Kingdom. *Qualitative Health Research*, 19, 1060-1075.
- Beckerman, N. L. (2002). Couples coping with discordant HIV status. *AIDS Patient Care and STDs*, 16, 55-59.
- Bernal, G., Maldonado-Molina, M. M., & Scharrón del Río, M. R. (2003). Development of Brief for Social Support: Reliability and Validity in Puerto Rico. *International Journal of Clinical and Health Psychology*, 3, 251-264.

- Bova, C., & Durante, S. (2003). Sexual functioning among HIV-infected women. *AIDS Patient Care*, 17, 75-83.
- Buchacz, K., Van der Straten, A., Saul, J., Shiboski, S. C., Gomez, C. A., & Padiau, N. (2001). Sociodemographic, behavioral, and clinical correlates of inconsistent condom use in HIV-serodiscordant heterosexual couples. *Journal of Acquired Immune Deficiency Syndrome*, 28, 289-297.
- Carrobles, A., Remor, E., & Rodriguez-Almorra, L. (2003). Afrontamiento, apoyo social percibido y distres emocional en pacientes con infección por VIH. *Psicothema*, 15, 420 426.
- Castro, A. (2005). Adherence to Antiretroviral Therapy: Merging the Clinical and Social Course of AIDS. PLoS Med 2(12): e338 doi:10.1371/journal.pmed.0020338
- CDC. (2011a). Diagnoses of HIV infection, by race/ethnicity and selected characteristics, 2009—40 states with confidential name-based HIV infection reporting. HIV Surveillance Report, 21, 25. Accessed on August, 12, 2012 at:
- http://www.cdc.gov/hiv/surveillance/resources/reports/2009report/pdf/table3a.pdf
- CDC. (2011b). Social Determinants of Health. Accessed on August, 12, 2012 at: http://www.cdc.gov/socialdeterminants/FAQ.html
- Checton, M., Green, K., Magsamen-Conrad, K., & Venetis, M. (2012). Patients' and partners' perspectives of chronic illness and its management. *Families, Systems and Health*, 30, 114-129.
- Commission on Social Determinants of Health. (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. *Final Report of the Commission on Social Determinants of Health*. World Health Organization: Geneva.
- Darbes, L., Chakravarty, S., Beougher, C., Neilands, T., & Hoff, C, (2011). Partner-Provided Social Support Influences Choice of Risk Reduction Strategies in Gay Male Couples. *AIDS Behavior*, DOI 10.1007/s10461-010-9868-8.
- Desgrées-du-Loû, A., & Orne-Gliemann, J. (2008). Couple-centred testing and counselling for HIV serodiscordant heterosexual couples in sub-Saharan Africa. *Reproductive health matters*, 16(32), 151-161.
- DiMatteo, M. R. (2004) Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis. *Health Psychology*, 23, 207-218.
- Dunbar, P. J., Madigan, D., Grohskopf, L. A., Revere, D., Woodward, J., Minstrell, J., ... Hooton, T. M. (2003). A two-way messaging system to enhance antiretroviral adherence. *Journal of American Medical Information Association*, 10, 11-15.
- El-Bassel, N., Witte, S. S., Gilbert, L., Wu, E., Chang, M., Hill, J., & Steinglass, P. (2003). The efficacy of a relationship-based HIV/STD prevention program for heterosexual couples. *Journal Information*, *93*(6), 963–969.
- Erlen, J. A., Sereika, S. M., Cook, R. L., & Hunt, S. C. (2002). Adherence to antiretroviral therapy among women with HIV infection. *Journal of Obstetric Gynecology Neonatal Nursing*, 31, 470-477.
- Grinstead, O. A., Gregorich, S. E., Choi, K. H., & Coates, T. (2001). Positive and negative life events after counseling and testing: The voluntary HIV-1 counseling and testing efficacy study. *AIDS*, 15, 1045-1052.
- Grossman, C. I., Forsyth, A., Purcell, D. W., Allison, S., Toledo, C., & Gordon, C. M. (2011). Advancing novel HIV prevention intervention research with MSM—Meeting report. *Public Health Reports*, *126* (4), 472.

- Herbst, J. H., Kay, L. S., Passin, W. F., Lyles, C. M., Crepaz, N., & Marín, B. V. (2007). A systematic review and meta-analysis of behavioral interventions to reduce HIV risk behaviors of Hispanics in the United States and Puerto Rico. *AIDS and Behavior*, *11*(1), 25-47.
- Higgins, J. A., Hoffman, S., & Dworkin, S. L. (2010). Rethinking gender, heterosexual men, and women's vulnerability to HIV/AIDS. *American Journal of Public Health*, 100 (3), 435-445
- Hirsch, J., Meneses, S., Thomson, B., Negroni, M., Pelcastre, B., & del Rio, C. (2007). The inevitability of infidelity: Sexual reputation, social geographies, and marital HIV risk in rural Mexico. *American Journal of Public Health*, 97, 986-996.
- House, J. S. (1981). Work Stress and Social Support. Reading, Mass: Addison-Wesley.
 Johnson J. G., Alloy L. B., Panzarella C., Metalsky G. I., Rabkin J. G., Williams J. B. W. & Abramson L. Y. (2001). Hopelessness as a mediator of the association between social support and depressive symptoms. Journal of Counseling and Clinical Psychology, 69, 1056-1060.
- Joint United Nations Programme on HIV/AIDS. (2009). *AIDS Epidemic Update December 2009*. Accessed on August 15, 2012 at: http://data.unaids.org/pub/report/2009/jc1700 epi update 2009 en.pdf
- Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.
- López, E. J., Jones, D. L., Villar-Loubert, O. M., Arheart, K. L., & Weiss, S. M. (2010).
- Violence, coping, and consistent medication adherence in HIV-positive couples. *AIDS Education and Prevention*, 22, 63-70.
- Machtinger, E., & Bangsberg, D. (2006). Adherence to HIV Antiretroviral therapy. *HIV InSite*. Manfrin-Ledet, L., & Porche, D.J. (2003). The state of science: Violence and HIV infection in women. *Journal of the Association on Nurses in AIDS Care*, 14, 56-58.
- McDowell, T. (2008). The relationship between social network characteristics and mental health for women living with HIV. Doctoral Dissertation. The Ohio State University. Acceded on August 15, 2012 at: http://etd.ohiolink.edu/view.cgi?acc_num=osu1228197342
- Miller, G. E. & Cole, S. W. (1998). Social relationships and the progression of human immunodeficiency virus infection: A review of evidence and possible underlying mechanisms. *Annals of Behavioral Medicine*, 20 (3), 181-189.
- Miller, R.L. (2001). Innovation in HIV prevention: Organizational and intervention characteristics affecting program adoption. *American Journal of Community Psychology*, 29, 621-647.
- Mills, E. J., Nachega, J. B., Bangsberg, D. R., Singh, S., Rachlis, B., Wu, P., ... Cooper, C. (2006) Adherence to HAART: A systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Med*, 3: e438 doi:10.1371/journal.pmed.0030438
- Murphy, D. A., Greenwell, L., & Hoffman, D. (2002). Factors associated with antiretroviral adherence among HIV-infected women with children. *Women Health*, 36, 97-111.
- National Collaborating Centre for Infectious Disease. (2010). *Interventions to prevent HIV transmission in serodiscordant couples*. Acceded on September 2, 2012 at: http://www.nccid.ca/files/serodiscordant couples.pdf
- Nieves-Lugo, K., & Toro-Alfonso, J. (2012). Challenges to antiretroviral adherence: Health beliefs, social support and gender roles in non-adherent men living with HIV in Puerto Rico. In C. García, R. Ballester, & J. A. Piña (Eds.), *Chronic Diseases and Medication Adherence*

- *Behaviors: Psychological Research in Ibero-American Countries* (pp. 153-173). New York, NY: Nova Sciences Publishers.
- Olapegba, P. O. (2005). Coping among People Living With HIV/AIDS (PLWHA): The influence of social support, self-esteem, locus of control and gender. *African Journal for the Psychological Study of Social Issues*, 8, 114-120.
- Orengo-Aguayo, R., & Pérez-Jiménez, D. (2009). Impact of relationship dynamics and gender roles in the protection of HIV discordant heterosexual couples: An exploratory study in the Puerto Rican context. *Puerto Rico health sciences journal*, 28 (1), 30-39.
- Ortiz-Torres, B., Serrano-García, I., & Torres-Burgos, N. (2000). Subverting culture: Promoting HIV/AIDS prevention among Puerto Rican and Dominican. *American Journal of Community Psychology*, 28, 859-882.
- Osterberg, L. and Blaschke, T. (2005). Adherence to medication. *The New England Journal of Medicine*, 353,487-497.
- Persson, A. (2008). Sero-silence and sero-sharing: Managing HIV in serodiscordant heterosexual relationships. *AIDS Care*, 20, 503-506.
- Phillips N., & Ardí, C. (2002). *Discourse analysis: Investigating processes of social construction*. Thousand Oaks, California.
- Poland, D. B. (2002). Transcription quality. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method.* (pp. 629 649). Thousand Oaks, CA: Sage.
- Power R., Koopman C., Volk J., Israelski D. M., Stone L., Chesney M. A., & Spiegel D. (2003) Social support, substance use, and denial in relationship to antiretroviral treatment adherence among HIV-infected persons. *AIDS Patient Care and STDs*, 17, 245-252.
- Pérez-Jiménez, D. & Orengo-Aguayo, R. E. (2011). Qualitative Analysis of an Educational Intervention with HIV-Discordant Heterosexual Latino Couples. *Puerto Rico Health Science Journal*, 30(4), 188-194.
- Pérez-Jimenez, D., Serrano-García, I., & Escabí Montalvo, A. (2007). Men's role in HIV/AIDS prevention for women: Exploring different views. *Puerto Rico Health Sciences Journal*, 26(1), 13-22.
- Pérez-Jiménez, D., Seal, D. W., & Serrano-García, I. (2009). Barriers and facilitators of HIV prevention with heterosexual Latino couples: Beliefs of four stakeholder groups. *Cultural Diversity and Ethnic Minority Psychology*, *15*(1), 11-17.
- Puerto Rico AIDS Surveillance Report. (2011). Department of Health. San Juan, PR.
- Remien, R. H. & Stirratt, M. (2002, January). Research with Couples of Mixed HIV Status Identifying Mutual Concerns, Fostering Mutual Care-Taking. *Body Positive*, 1, 1-2.
- Remien R.H., Halkitis P.N., O'Leary A., Wolitski R.J., & Gómez C.A., (2005). Risk perception and sexual risk behaviors among HIV-positive men on antiretroviral therapy. *AIDS and Behavior*, 9, 167–176.
- Rispel, L., Metcalf, C., Moody K., & Cloete, A. (2009). Exploring Coping Strategies and Life Choices made by HIV Discordant Couples in Long-Term Relationships: Insights from South Africa, Tanzania and the Ukraine. Retrieved from: http://www.hsrc.ac.za/research/output/outputDocuments/5667_Rispel_HIVdiscordantcouples.pdf
- Robbins, R. N., D'Aquila, E., Morgello, S., Byrd, D., Remien, R. H., & Mindt, M. R. (2012). Cultural Influences on Antiretroviral Therapy Adherence Among HIV-Infected Puerto Ricans. *Journal of the Association of Nurses in AIDS Care*, PMID: 22525858.

- Roberts, K. J., & Mann, T. (2000). Barriers to antiretroviral medication adherence in HIV-infected women. *AIDS Care*, 12, 377-386.
- Rodríguez-Madera, S., & Varas-Díaz, N. (2012). Puerto Rican heterosexual HIV-Discordant couples: Cultural challenges for healthy couples. In K. Organista (Ed), *HIV Prevention with Latinos: Theory, Research, and Practice* (pp. 227-244). London: Oxford University Press.
- Rodríquez Madera, S., & Marqués Reyes, D. J. (2006). Las relaciones de parejas como espacios para el descontrol: la trasgresión de la de manda preventiva ante el VIH. *Ciencias de la Conducta*, 21, 97-128 Schwandt, T. A. (2001). *Dictionary of qualitative inquiry*. Thousand Oaks, CA: Sage.
- Shandor-Miles, M., Roman-Isler, M., Banks, B. B., Sengupta, S., & Corbie-Smith, G. (2010). Loneliness: Socialemotional Suffering in African Americans Living With HIV in the Rural South. *Qualitative Health Research*, 21(4) 489-501.
- Simoni, J. M., Yang, J. P., & Porricolo, M. (2012). Families and HIV Medication Adherence. In W. Pequegnat, & C. C. Bell (Eds.), *Family and HIV/AIDS: Cultural and Contextual Issues in Prevention and Treatment* (pp. 209-226). New York, NY: Springer.
- Starace, F., Ammassari, A., Trotta, M. P., Murri, R., De Longis, P., Izzo, C., ... Antinori, A. (2002). Depression is a risk factor for suboptimal adherence to highly active antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndrome*, 15, 136-139.
- Stevens, P. E., & Galvao, L. (2007). "He Won't Use Condoms": HIV-Infected Women's Struggles in Primary Relantionships With Serodiscordant Partners. *American Journal of Public Health*, 97, 1015-1022.
- The California Partners Study. (1999). The management of HIV, sex and risk among serodiscordant heterosexual couples. Presentation at the National Conference of Women & HIV. Los Angeles, CA.
- Toro-Alfonso, J., Andújar-Bello, I., Amico, R., & Fisher, J. D. (2002). *Psychosocial implications and level of adherence to treatment in a sample of people living with HIV/AIDS in Puerto Rico*. Presentation at the International Conference on AIDS, July 7-12. Abstract no. B10436.
- Toro-Alfonso, J., & Varas-Díaz, N. (2004). El desarrollo de redes de apoyo para hombres que tienen sexo con hombres y que viven con VIH/SIDA: Alternativa para la intervención en política pública. In C. Caceres, T. Frasca, M. Pecheny, & V. Terto (Eds.), *Ciudadania sexual en America Latina: Abriendo el debate* (pp. 79-92). Lima. Peru: Universidad Cayetano Heredia.
- Uchino, B. N. (2009). Understanding the Links Between Social Support and Physical Health. A Life-Span Perspective With Emphasis on the Separability of Perceived and Received Support. *Perspectives on Psychological Science*, *5*(4), 236-255.
- Uchino, B. (2006). Social Support and Health: A Review of Physiological Processes Potentially Underlying Links to Disease Outcomes. *Journal of Behavioral Medicine*, 29(4), 377-387.
- USAID & AIDSTAR-One. (2010). HIV prevention for serodiscordant couples. Acceded on August 15, 2012 at: http://www.aidstar
 - one.com/focus_areas/prevention/resources/technical_briefs/serodiscordant_couples_hiv_p revention
- VanDevanter, N., Thacker, A. S., Bass, G., & Arnold, M. (1999). Heterosexual couples confronting the challenges of HIV infection. *Aids Care*, 11(2), 181-193.

- Wagner, G. J., Remien, R. H., Carballo-Dieguez, A., & Dolezal, C. (2002). Correlates of adherence to combination ntiretroviral therapy among members of HIV-positive mixed status couples. *AIDS Care*, 14, 105-109.
- Weinhardt, L.S., Kelly, J.A., Brondino, M.J., Rotheram-Borus, M. J., Kirshenbaum, S. B., Chesney, M. A., ... Gore-Felton, C. (2004). HIV transmission risk behavior among men and women living with HIV in 4 cities in the United States. *Journal of Acquired Immune Deficit Syndrome*, 36, 1057-1066.
- WHO. (2003). Social determinants of health: The solid facts. Acceded on August 17, 2012 at: http://www.euro.who.int/ data/assets/pdf file/0005/98438/e81384.pdf
- WHO. (2012). Antiretroviral therapy. Acceded on December 26, 2012 at: http://www.who.int/topics/antiretroviral_therapy/en/
- Wilson, T.E., Gore, M. E., Greenblatt, R., Cohen, M., Minkoff, H., Silver, S., ... Gange, S. J. (2004). Changes in sexual behavior among HIV-infected women after initiation of HAART. *American Journal of Public Health*, 94, 1141-1146.
- Woods, S. P., Dawson, M.S., Weber, E., Gibson, S., Grant, 1., & Atkinson, J. H. (2009). Timing is everything: Antiretroviral non-adherence is associated with impairment in Challenges to Antiretroviral Adherence 173 time-based prospective memory. *Journal of International Neuropsychological Society*, 15, 42-52.
- Wrubel J., Stumbo S., & Johnson M. O. (2010). Male Same Sex Couple Dynamics and Received Social Support for HIV Medication Adherence. *Journal of Social and Personal Relationships*, 27, 553-572.
- Young, J., De Geest, S., Spirig, R., Flepp, M., Rickenbach, M., Furrer, H., ... Vernazza, P. (2004). Stable partnership and progression to AIDS or death in HIV infected patients receiving highly active antiretroviral therapy: Swiss HIV cohort study. *British Medical Journal*, 328, 15-18.