ORIGINAL RESEARCH

# Prevalence and correlates of serostatus disclosure in HIV-infected adults attending the follow up and treatment clinic in Barbados

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**Abstract**

Objective: To determine the extent of disclosure and factors associated with disclosure of HIV status to sexual partners, we interviewed HIV infected adults attending the centralized HIV clinics seeking medical care for HIV. Methods: The subjects were patients who attended the Ladymeade Reference Unit (LRU) for primary care and treatment of their HIV infection during the three months period of this study enrolment. Patients were asked to participate in this study after initial clinical care was performed, and had a 30-minute standardized interview concerning behavioral, medical, and social history. Results: The study patients had the following characteristics: female, 42.7%; male, 57.3%; singles, 84.5%; married, 11.8%. The median age of respondents was 35 years, and 66.4% were employed. Seventy nine percent were sexually active, and of these 72% had a steady sex partner and 61% had one or more casual partners. Over all 64 (58.2%) of those interviewed, had disclosed their HIV status to significant others. Of the sixty three persons who had a steady partner 71.4% had self disclosed their HIV status to their steady partner. Of the fifty three persons who had one or more casual partners, 26.4% had self-disclosed their status to one or more casual partners. The most common reasons listed for nondisclosure to spouse or significant other were stigma/discrimination, fear of spread of information's, and rejection. Conclusion: Our findings suggest that both the knowing and unknowing sexual partners of HIV-infected persons continue to be at risk for HIV transmission.

## Introduction

Sexual responsibility and honest disclosure by sero-positive individuals remain at the center of HIV prevention (1). However, practical and psychological difficulties of disclosure do exist for sexually active individuals living with HIV (2). Decisions about disclosure of HIV status to the significant others involves anxiety, stigma, and shame and a host of other economic, psychological and emotional issues (3, 4). Divulging to sexual partners may lead to isolation or even physical abuse (4). The public health significance of nondisclosure, however, depends on both its prevalence and the risky-ness of the behaviors that occur without disclosure, that is, the extent to which sex without disclosure is unprotected and sex between sero-discordant partners. Previous studies show that not disclosing positive HIV sero-status to at least some sexual partners is common (5-7), that HIV-positive persons are more likely to disclose their status to steady partners than to non-steady partners (8-10), and that unprotected sex without disclosure occurs within both types of partnerships (5-9). In our own study we found that only 28% of post-parturient HIV infected women had disclosed their HIV status to significant others among the HIV infected post-parturient women, however, this study was limited to post parturient women (11). Data regarding the reason for non-disclosure among HIV infected women and men in the

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Caribbean region are limited (11, 12), and little is known about the prevalence of the risk taking behaviors in this population and the prevalence of sex between sero-discordant partners.

In this study we explored the prevalence and the factors associated with non-disclosure among the HIV infected adults attending the HIV/AIDS follow up and treatment clinic in Barbados. We also studied the extent of the risk taking behavior in this population that would be conducive to HIV transmission in this community.

## Patients and methods

The Ladymead Reference Unit (LRU) located at the Ladymeade Garden, in the parish of St. Michael is the centralized HIV/AIDS clinic meant to be the one stop ambulatory care and treatment facility for all HIV infected persons in this country. This center is responsible for the initial assessment, follow up and care and treatment of all adult patients with HIV infection in Barbados. Referrals come from a variety of sources including inpatient hospital services and emergency department at the Queen Elizabeth Hospital, and the community health centers, Drug treatment programs, HIV testing sites, prisons, and private office of the General practitioners spread through out this country.

The subjects for this study were patients who attended the LRU for the first time for primary care and treatment of their HIV infection during the three months period of this study enrolment. All the patients attending the LRU for the first time during the period, from August 2005 to October 2005 were enrolled into this study. Any of the subjects who presented more than once to the LRU during the three months study enrolment period were excluded from enrollment during the second and subsequent visits. Thus each subject was enrolled only once to avoid any duplication of study subjects. Each patient provided verbal informed consent prior to entering the study. All the participants to this study were assured of confidentiality. Participants were informed that their participation or non-participation was purely voluntary and that it will not affect their future care and treatment in anyway. Ethical approval for this study was obtained from the Ethics Committee at the Ministry of Health, Government of Barbados through the Director of Medical services at the LRU.

Patients were asked to participate in this study after initial clinical care was performed, including history taking, physical examination, and laboratory tests. This delay provided some opportunity for the study subjects and the interviewers to familiarize themselves with each other and to develop some rapport and confidence in each other facilitating communication. Patients agreed to participate in a 30-minute standardized semi-structured interview probing into their behavior including disclosure of their HIV status to significant others, and their medical and social history. To optimize truthfulness of patient reports, interviews were conducted in private settings by interviewer who is one of the authors of this paper and was involved in the patients' clinical care. Great care was taken to insure that the interviewer was non-judgmental. Patients were once again assured that no information collected would be reported to any of their other patient care team member or recorded in the medical record.

The primary outcome of interest was whether the HIV infected persons disclose their status to all their sexual partners. Patients were probed for sexual activity since their diagnosis of HIV infection, number of steady and casual sex partners since diagnosis of their HIV infection and the disclosure of their HIV status to each of these partners and to significant others including parents, siblings, children and friends. Reason for their disclosure or non disclosure of their HIV status to others was also probed. Independent variables examined included demographics such as age, sex, education -less than high school graduation or high school graduate, employment, HIV transmission risk group (injection drug use, men who have sex with men or heterosexual), and number of sexual partners in the past year (1 vs. $\geq 2$), history of physical or sexual violence, history of injection drug use, and alcohol abuse. Frequency of condom use was assessed (all the time vs. most, or none of the time) and considered an independent variable. Clinical variables included HIV-related physical symptoms (HIV illness class), duration of HIV diagnosis, and CD4 cell count obtained within 3 months of initial medical evaluation; when 2 counts were available we used the mean count.

Descriptive statistics were generated for each independent variable; bi-variate analyses were then conducted between each independent variable and disclosure status, using 2 independent sample t tests and chi squared analysis for continuous and discrete independent variables, respectively. A 2-tailed $P<.05$ was considered statistically significant in bi-variate and multivariable analyses. Data were analyzed using SPSS statistical software (SAS Institute Inc, Cary, NC).

## Results

One hundred ten eligible HIV infected persons who presented for follow up care and treatment of their HIV infection at the Ladymeade Reference Unit were interviewed. Enrolled patients represented 84% of all the HIV infected persons presenting to LRU for follow up care and treatment for the first time. There were no significant differences between persons who enrolled and those who did not enroll in the study with respect to age, sex, and HIV risk group category. Sociodemographic characteristics of the study population are shown in Table 1. The median age of respondents was 35 years (Inter Quartile Range – IQR, 26 – 41 years). Compared with males, females were more likely to be younger than 35 years (42.8% vs. 59.6%), and high school graduates (73.1% vs. 87.2%); and less likely to be single (88.8% vs. 78.7%) and employed (66.6% vs. 65.9%). However, none of these differences were statistically significant (P=0.061). Regarding transmission risk group, all females were heterosexual. Where as, of the men, 79.4% were heterosexual, and 20.6 % were homosexual or bisexual. There were no injection drug user; however, 14.5% smoked marijuana.

Fifty three (48.2%) respondents were diagnosed to be HIV infected from HIV testing during an illness suspected to be associated with HIV infection, 34 (30.9%) were diagnosed from the antenatal voluntary counseling and testing, 14 (12.7%) persons were diagnosed from voluntary testing of non-pregnant otherwise healthy persons and the remainder were tested for other reasons such as for insurance or immigration purposes The median CD4 cell count at the time of their interview or with in 3 months prior to their interview was 306 cells/microliters (IQR, 162 – 412). Forty two (40.8%) had a CD4 cell counts < 200 cells/microliters. Over all the median time period since their diagnosis up to the time of this interview was 15 months (Range = 1 month to 126 months). The Median time since diagnosis was 18 months (Range = 1 month to 126 months) for the females and 13 months (Range 2 months to 86 months) for males. Eighty (72.7%) persons were on HAART at the time of their interview including 31(61.7%) females and 49(76.2%) males

**Table 1**
**Selected sociodemographic characteristics of the HIV infected adults who were surveyed**

| | | **Females** (n=47) | **Males** (n=63) | **Overall** (n=110) |
|---|---|---|---|---|
| ***Age Group (years)*** | 16-25 | 6 (12.8) | 6 (9.5) | 12 (10.9) |
| | 26-35 | 22 (46.8) | 21 (33.3) | 43 (39.1) |
| | 36-45 | 15 (31.9) | 20 (31.7) | 35 (31.8) |
| | 46-55 | 4 (8.5) | 14 (22.2) | 18 (16.4) |
| | 56-65 | 0 (0) | 2 (3.2) | 2 (1.8) |
| ***Marital status*** | Single | 37 (78.7) | 56 (88.8) | 93 (84.5) |
| | Married | 6 (12.7) | 7 (11.2) | 13 (11.8) |
| | Separated | 4 (8.6) | 0 (0) | 4 (3.7) |
| ***Education*** | Primary | 6 (12.8) | 17 (26.9) | 23 (20.9) |
| | Secondary | 31 (65.9) | 34 (54) | 65 (39.1) |
| | Tertiary | 10 (21.3) | 12 (19) | 22 (20) |
| ***Employment*** | Employed | 31 (65.9) | 42 (66.6) | 73 (66.4) |
| | Unemployed | 17 (34.1) | 20 (33.3) | 37 (33.6) |

**Table 2**
**Selected life style and HIV disease status related characteristics of the HIV infected adults who were surveyed**

| | **Females** | **Males** | **Over all** |
|---|---|---|---|
| ***Sexually active since diagnosis of HIV*** | **n=47** | **n=63** | **n=110** |
| Yes | 39 (83) | 48 (76.2) | 87 (79.1) |
| No | 8 (17) | 15 (23.8) | 23 (20.9) |
| ***Number of sex partners since diagnosis of HIV for those who were sexually active*** | **n=39** | **n=48** | **n=87** |
| 1 | 21 (53.8) | 20 (41.6) | 41 (47.1) |
| 2 | 5 (12.8) | 10 (20.8) | 15 (17.2) |
| ≥ 3 | 13 (33.3) | 18 (37.5) | 31 (35.6) |
| ***Steady partners for those who were sexually active since diagnosis*** | **n=39** | **n=48** | **n=87** |
| *Yes* | 30 (76.9) | 33 (68.7) | 63 (72.4) |
| *None* | 9 (23.1) | 15 (31.3) | 24 (27.6) |
| ***Casual partners for those who were sexually active since diagnosis*** | **n=39** | **n=48** | **n=87** |
| None | 18 (46.1) | 16 (33.3) | 34 (39.1) |
| 1 | 7 (17.9) | 9 (18.7) | 16 (18.4) |
| 2 | 7 (17.9) | 8 (16.7) | 15 (17.2) |
| ≥ 3 | 7 (17.9) | 15 (31.2) | 22 (25.3) |

Overall eighty seven (79.1%) persons including 39 (83%) females and 48(76.2%) males were sexually active at some point of time since the diagnosis of their HIV infection (Table 2). From among those sexually active, 45(52.9%) including 18 females (46.2%) and 27 males (58.4%) had two or more sex partners since the time of their diagnosis. Sixty three (72.4%) persons had one or more (in succession, one after the other) steady sex partner and fifty three (60.9%) persons had one or more (mostly in succession, one after the other but sometimes at the same time) casual partners since time of the diagnosis of their HIV infection. Compared to males, more females had steady sex partner (68.7% vs. 76.9%) and less female had casual sex partners (66.7% vs. 57.9%). However, these differences were statistically not significant (P=0.053). Fifty percents of females who reported to have had steady sex partner, had more than one steady sex partner at different times and 33% of males who reported to have had steady sex partner had more than one

**Table 3**
**Prevalence of disclosure to significant others among HIV infected adults who were surveyed**

| | Females | Males | Over all |
|---|---|---|---|
| ***Over all disclosure to significant others*** | **n=47** | **n=63** | **n=110** |
| One or more of the sex partners | 18 (38.3) | 34 (54) | 52 (47.2) |
| One or more of family members | 28 (59.6) | 32 (50.8) | 60 (54.5) |
| One or more of friends | 9 (19.1) | 10 (15.9) | 19 (17.2) |
| Not disclosed to anybody | 15 (31.9) | 18 (28.6) | 33 (30) |
| ***Disclosure to sex partners*** | | | |
| **Steady partners** | **n=30** | **n=33** | **n=63** |
| All steady partners | 9 (30) | 11 (33.3) | 20 (31.7) |
| Some steady partners | 13 (43.3) | 12 (36.4) | 25 (39.7) |
| None | 8 (26.7) | 10 (30.3) | 18(28.6) |
| **Casual partners** | **n=21** | **n=32** | **n=53** |
| All the casual partners | 2 (9.6) | 4 (12.5) | 6 (11.3) |
| Some casual partners | 5 (23.8) | 5 (15.6) | 10 (18.9) |
| None | 14 (66.7) | 23 (71.9) | 37 (69.8) |
| ***Disclosure to Employer*** | **n=12** | **n=19** | **n=31** |
| Yes | 0 (0.0) | 1 (5.3) | 1 (3.2) |
| No | 12 (100) | 18 (94.7) | 28 (96.8) |

steady partner in succession. However, once again these differences were statistically not significant (P=0.66).

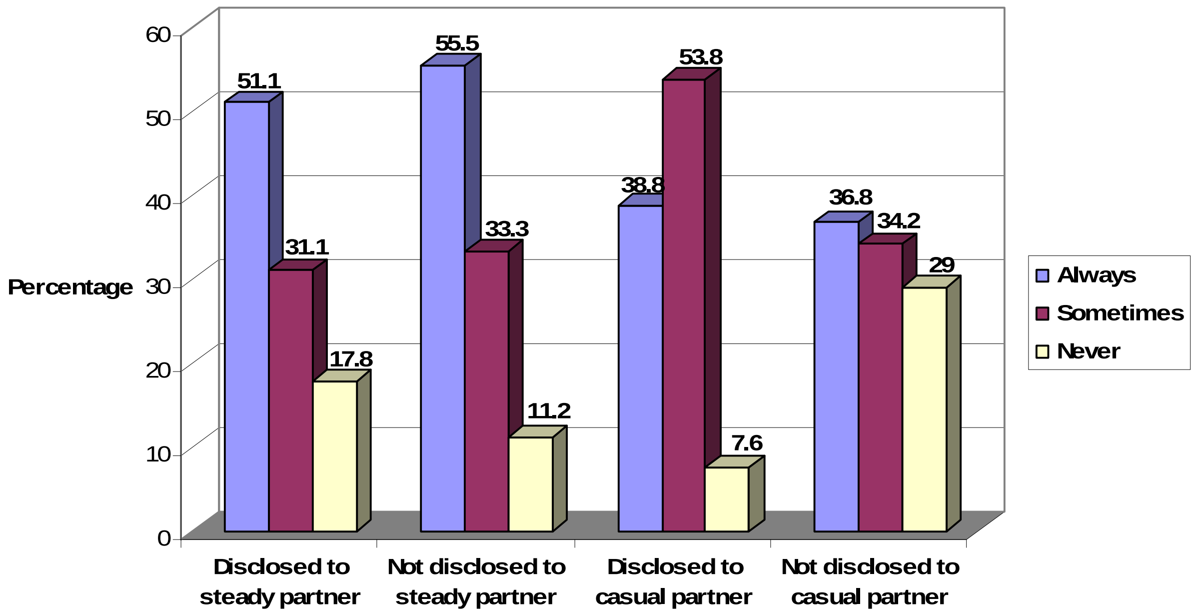
Overall, 64 (58.2%) of those interviewed, had disclosed their HIV status to significant others while 46(41.8%) had not disclosed their HIV status to any body, other than their health care providers. Sixty (54.5%) persons had disclosed their HIV status to one or more of their family members other than their sex partner and 52(47.2%) had disclosed their HIV status to one or more of their sex partners (Table 3). All those persons who had disclosed their HIV status to one or more of their sex partners had also disclosed their HIV status to one or more of their family members. Only 1 person had self disclosed his status to his employer. Disclosure pattern among the 47 females was as follows- to one or more family members (59.6%), including sisters, aunts and mother in that order of frequency; to one or more sex partners (38.3%); and one or more friends (19.1%). Disclosure pattern among the 63 males was as follows- to one or more family members (50.8%), including sisters and mother in that order of frequency; to one or more sex partners (54%) and friends (28.6%). There were no significant difference (P=0.051) between disclosure pattern among the males and the females. Sixty three persons who had a steady partner at the time of their interview, 31.7% had self disclosed their HIV status to their steady partner. Fifty three persons who had one or more casual partners, 11.3% had self-disclosed their status to all of the casual partners and additional 18.9% had disclosed to some of their casual partners. These differences in the rate of disclosure to steady and casual partners was statistically significant (p = 0.034). Of the 42 persons with a CD4 cell counts < 200 cells/microliter, 35(83.3%) had disclosed their HIV status to at least some other persons, where as from among the 61 persons with a CD4 cell counts ≥ 200 cells/microliter, 26(42.6%) had disclosed to significant others (p = 0.039).

Of the 23 females who had disclosed their HIV status to their steady partner, 10 reported that their steady partner was tested for HIV with 6 of them being positive for HIV infection as well. Among 25 male respondents who reported to have disclosed their HIV status to the steady partner, 19 were tested with 6 of them being positive for the HIV infection.

Many (71.4%) of the respondents who had not disclosed their HIV status to the significant others, gave more than one reason for their non disclosure. Common reasons for nondisclosure to spouse or significant others as stated by the respondents included: fear of some form of stigma/discrimination (n=33), expressed in statements such as “them will treat me bad”; fear of spread of the information and exposure in the society and other ill consequences (n=28), typified by replies such as “they talk too much/them will spread the news”; fear of rejection by the spouse/sex partner or the family (n=17), as expressed in statements like “he will stop seeing me”; and denial of their HIV infection (n=13), as reflected in their expressions such as “ I don’t have no virus”, or “everything will be ok”. Other reasons stated by the respondents included; "need to deal with my own emotions first" (n=5), “it aint nobody’s business” (n=4), "them people will not be able to handle it" (n=4), “don’t wanna loose my job” (n=3) and “don’t trust nobody” (n=3). Nearly a fourth (n=11) of the respondents who had not disclosed their HIV status did not give any reason for their nondisclosure. Nearly a third (60.9%) of those who had disclosed their HIV status to significant others, did not give any reason for their disclosure. Common reasons given for disclosing their HIV status were as followings: trust in the partner or family members (n=37) as exemplified by responses such as “I trust he”; anticipating care and support from the partner or family members (n=32) expressed as “I tell them so that them will care for my little boy when I get sick”; and protection of their sex partner against possible transmission of her HIV infection (n=9) as reflected in response such as “ I told my man so that we could use rubber every time we have sex”. All of those persons, who gave reason for disclosure, gave multiple reasons.

Prevalence of condom use is shown in figure 1. Over all, of 87 persons who reported to be sexually active since the time of their diagnosis, 17 (19.5%) used condoms all the time while an additional 24 (27.6%) used condom some of the time during the sexual intercourse during the past one month. There were no significant difference between the male and female gender and the use of condom during sexual intercourse over the past month (P=0.103). Also there was no significant difference in condom use rate among those who disclosed and those who did not disclose the HIV status to their steady partner (P=0.053). However, a significantly higher proportion (29% vs. 7.6%) of women who did not disclosed their HIV status to their casual partners reported to have never used condoms as compared to those who disclosed the HIV status to their casual partners (P=0.02).

**Figure 1. Condom use among the HIV infected indivisuals and HIV serostatus disclosure.**



## Discussion

The findings from this study shows that a high proportion of those HIV infected are sexually active often with multiple steady and or casual sex partners. Many of these individuals have been infected for over a year and a significant proportion had progressed to an advanced stage of the HIV disease. It has been shown that the HIV-infected individuals have poor knowledge regarding their partners' infection status (15). This may influence sexual behaviors that result in increased transmission. Therefore, this population has the combination of factors conducive for the HIV transmission in this community unless people make effort for honest disclosure to their sexual partners and practice safer sex.

Over two-fifths of all the new attendants to the HIV follow up clinic had not disclosed their HIV status to any body other than the health care givers and over three-fourths of these new attendants who were HIV infected and sexually active had not disclosed their HIV status to one or more of their sex partners. There are several factors that discourage people from self disclosing their HIV status to others. First, there are psychological consequences of disclosure, especially the risk of rejection. The reasons for nondisclosure to significant others and spouses listed by respondents speak to the many ways that this fear manifests. Although, some of these fears may be perceived fears, there are real psychosocial consequences of self disclosure (2, 4, 16). Also, there are practical social ramifications-desired sexual encounters may be missed, financial or sick care support may be denied. Third, HIV-infected individuals may rationalize that their partners need to protect themselves; thus, it is every individual's responsibility. Why risk the possible losses described above? Perhaps those who do not disclose believe they are not putting others at risk, or at very low risk, because they are avoiding specific higher-risk practices such as anal intercourse, or because they are regularly using condoms. Yet arguments have been made that partners would want to know HIV status even within the context of safer sex. Further more, HIV-infected individuals have poor knowledge regarding their partners' infection status (15).

In our study, disclosure to casual sex partners was significantly less common as compared with the disclosure to the steady sexual partners.

Individuals may feel different responsibilities to different partners. We found that both men and women are far more likely to disclose to steady partners than to casual partners. Studies have also found that homosexual men are far more likely to disclose to intimate or steady partners than to casual or non-primary partners (5, 6, 13, 14). Less frequent disclosure to casual sex partners as compared to the steady sex partners have been reported in another study as well (17). Of note, there is at least one report of increased rate of disclosure to casual sex partner as compared to steady sex partner (18). These reports indicated that researchers looking at disclosure behavior should be aware of varying disclosure contexts as well as the emotional consequences impacting disclosure decision-making within these contexts.

We did not find any significant difference in the frequency of protected sexual activity among those who disclosed and those who did not disclose their HIV status to their sex partners. In either category only half of these individuals used condoms consistently while having sex with their steady partner and only a little over one-third used condoms consistently while having sex with their casual partner. Disclosure alone does not bring an automatic change in sexual behavior has been shown in other studies (19, 20). Interventions for seropositive men that focus primarily on increasing disclosure of serostatus to sex partners may not reduce the prevalence of unsafe sex. Interventions are needed to address the social and psychologic processes that give rise to risky behavior patterns in HIV-infected men. Behavioral interventions that enhance seropositive persons' skills in communicating explicitly with partners about safer sex to help reduce transmission of HIV must be a part of the over all intervention program for these persons. At this point its noteworthy that most of these HIV infected persons had no psycho behavioral intervention beyond the pre and post HIV test counseling.

The findings from this study are especially important at this juncture of time in this countries fight against the HIV/AIDS epidemics when the government has put in huge efforts to curb this epidemic. There exists an excellent network of government run health care centers for easy accessibility and efficient delivery of health care to its population. There is provision of voluntary counseling and testing for HIV at all of these health centers and through the private office of general practitioners with a centralized facility for the care and treatment of HIV infected persons including HAART. What is even more remarkable is that all these services are without any direct cost to the public at the point of delivery. Therefore, the findings from this study makes a strong case for allocation of more efforts and resources for interventions aimed at reducing the stigmatization of HIV/AIDS and for assisting persons with HIV/AIDS to manage the stress of disclosure and address their social and economic concerns continue to be needed despite the advent of HAART. There is an urgent need to strengthen the counseling and social support system in the community to assist these individuals in making decisions for disclosure. The current strategy which focuses mostly on the pre and post HIV test counseling need to change to include provision for more comprehensive and repeated counseling of these individuals after their diagnosis in order to help them to cope up with the unfolding situations in their post diagnosis life and to enhance their capacity and the confidence to deal with this highly stigmatized illness.

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