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## Never in care: Characteristics of HIV-infected crack cocaine users in two U.S. cities who have never been to outpatient HIV care

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### Abstract

**Background**—There are very limited data available of the correlates of HIV-infected crack users who have never been to HIV care.

**Methods**—Interviews were conducted at bedside with HIV-infected crack cocaine users who were recruited from the inpatient wards at Jackson Memorial Hospital in Miami, FL and Grady Memorial Hospital in Atlanta, GA between August 2006 and July 2009. Participants were asked about their socio-demographic characteristics, drug use, drug/alcohol treatment history, use of HIV care, perceived social support, and mental health status. Multiple logistic regression was performed to identify factors associated with never having been to HIV care.

**Results**—Among 355 study participants, 21% reported never having been to a doctor or clinic for HIV care. Higher adjusted odds of never having been in care were associated with an annual income of less than \$5,000 (AOR=8.17, 95% CI=3.35–19.94, residence in Atlanta compared to Miami (AOR=2.57, 95% CI=1.36–4.83), no history of drug treatment (AOR=4.13, 95% CI=2.24,7.62) and not being helped into care at the time of HIV diagnosis (AOR=2.83, 95% CI=1.56,5.15).

**Conclusions**—Our data show that a significant proportion of HIV-infected crack cocaine users in two city hospitals have never been to HIV care. Interventions at the time of HIV diagnosis and drug treatment participation may facilitate linkage to care.

### Introduction

There has been little research that has sought to examine the characteristics of HIV-infected persons who have never been in HIV care. Regular HIV care is essential for persons living with HIV so that providers can assess their stage of HIV infection, assure patient understanding about HIV infection, and initiate antiretroviral treatment if clinically indicated [1]. The Ryan White Care Act was created to serve as a “safety net” to ensure that all patients living with HIV would receive care if no other funding mechanisms were provided [2].

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Previous studies have found poor utilization of HIV care to be associated with poverty, substance abuse, lack of social support, and absence of a regular source of primary health care [3–9]. Studies have also shown that specific patient populations, including African American, Hispanics, and illicit drug users, have been less likely to receive HIV care than HIV-positive persons not in these population groups [10–14]. However, there are very limited data available of the correlates of persons who have never seen an HIV care provider after receiving their HIV diagnosis. In this paper, we describe the prevalence and characteristics of never having been to a doctor or clinic for HIV care among a sample of HIV-infected crack users hospitalized in Atlanta and Miami.

## Methods

### Study population and Data collection

The study population was comprised of HIV-infected crack cocaine smokers recruited from the inpatient wards at Jackson Memorial Hospital in Miami, Florida and Grady Memorial Hospital in Atlanta, Georgia. Structured interviews were administered to eligible participants upon their enrollment in a behavioral intervention study for sexually active HIV-infected crack users called Project HOPE (Hospital Visit is an Opportunity for Prevention and Engagement with HIV-positive Crack Users). To be eligible, study participants were required to be HIV positive, report being sexually active during the previous 6 months, report use of crack cocaine during the previous 2 years and to be willing to provide contact information for study follow-up. Written informed consent was obtained from each eligible patient before enrollment into the study.

Between August 2006 and July 2009, face-to-face patient interviews were conducted at bedside at Jackson and Grady Hospitals using HAPI (Handheld Assisted Personal Interview). The structured interview lasted for approximately 2 hours and consisted of questions about socio-demographics, drug and sexual histories, psychosocial and clinical characteristics. All data remained confidential and participants were compensated \$25.00 upon completion of the interview. All research was reviewed and approved by the University of Miami and the Emory University institutional review boards, as well as the research oversight committees of Jackson Memorial Hospital and Grady Memorial Hospital.

### Measures

The dependent variable analyzed for this paper was defined as ‘Have you ever gone to a doctor or clinic for HIV care?’ as reported (yes/no) by study participants at the baseline interview. The independent variables examined for association of never being in care were classified as individual characteristics, drug use history, and psychosocial status and health system factors. The variables within each of these 4 categories were selected based on previous studies that had reported barriers to entry into HIV care [15–18].

### Independent variables

Individual characteristic variables included race (white, black-non Hispanic, Hispanic), marital status (single- never been married, divorced, separated, widowed, other), having any children (yes/no), age, gender (male/female), sexuality (heterosexual, homosexual, bisexual), self-reported annual income (<\$5,000 or ≥\$5,000), education ‘How much school have you completed?’ (elementary school, some high school, high school graduate, some college, college, graduate), homelessness ‘Are you currently homeless?’, disability funding status ‘Are you currently receiving disability?’ and history of time spent jail or prison ‘Have you ever been to jail or prison?’.

Drug use history variables included history of injection drug use (yes/no), recent history of crack use ‘When was the last time you used crack cocaine?’, frequency of crack use (everyday vs. less than everyday during the past 6 months), frequency of alcohol use (everyday vs. less than everyday during the past 6 months) and/or alcohol influence on seeking care ‘Did you ever put off seeking care because you were high on drugs or alcohol?’ (yes/no).

Psychosocial measures included perceived social support and depression. Social support was measured by the 19-item Social Provisions Scale (SPS) ( $\alpha=0.974$ ,  $n=19$ ) [19]. The scale consisted of four separate social support subscales: emotional/informational, tangible, affectionate, and positive social interaction, as well as an overall functional social support index. The overall support index was determined by the average of the scores for four subscales plus one additional item in the survey. Depression was measured using the Brief Symptom Inventory Depression Scale ( $\alpha=0.838$ ,  $n=6$ ).

Health system factors examined in the study consisted of time since initial HIV diagnosis, receipt of assistance for getting into care ‘Were you helped into care upon your initial HIV diagnosis?’ (yes/no), case manager referral ‘When you were first diagnosed with HIV were you referred to a case manager?’ patient knowledge of CD4 count (yes/no), patient knowledge of HIV-1 viral load (yes/no), medical care attitude- which assessed agreement/disagreement with statements like “I do not need medical care and HIV medicines until I get very sick” ( $\alpha=0.796$ ,  $n=7$ ), and recent history of hospitalization ‘How many times have you been hospitalized in the past 6 months?’ (0–96 times was the possible range).

History of ever drug treatment (yes/no) and drug treatment during the past 6 months (yes/no) were also included as health system variables.

## Data Analysis

Bivariate analyses were performed to describe the characteristics of HIV-infected crack cocaine users who self reported never being in care. For nominal-level independent variables, associations were assessed using chi-square tests of independence or Fisher’s exact test if the expected value of any cells was less than 5, and t-tests for continuous and interval-level independent variables. Multivariable logistic regression models were employed to assess variables associated with the dependent variable of never having been in HIV care. Multiple logistic regression modeling was conducted as outlined by Hosmer and Lemeshow [20]. In the multivariable logistic regression modeling, independent variables with p-values  $\leq 0.20$  in bivariate associations with the dependent variable were included in the initial model. SAS version 9.1.3 was used for statistical analysis.

## Results

### Individual characteristics

Between August 2006 and July 2009, 355 HIV-infected crack cocaine users who were patients hospitalized at Grady Memorial Hospital or Jackson Memorial Hospital were enrolled into Project HOPE and completed a baseline interview. The study population was slightly over half female (52%), 74% were 40 years of age or older, 65% were single and never married and the majority (90%) were Black, non-Hispanic. Educational achievement was low with 51% reporting less than a high school diploma or equivalent, and 43% of patients were receiving disability funding. Most participants (65%) reported annual incomes of less than \$5,000, were unemployed (96%), had spent time in jail or prison (90%), and 43% reported that they were currently homeless (defined as not having their own place to sleep, including a friend’s or family’s place). The individual characteristics of the study population are shown in Table 1.

## Drug use history

The majority (85%) of participants reported use of crack during the 3 months prior to interview. More than one third of participants (38%) considered themselves as 'everyday crack users' (smoking crack one or more times a day), and 38% reported being high from crack cocaine at the time of their last sexual intercourse. The drugs most frequently used by participants in the past six months included crack cocaine (92%), marijuana (41%), powder cocaine (16%) and heroin (3%). Approximately one fifth of participants (22%) reported ever having injected any drugs not prescribed by a doctor, although only 3% reported having injected drugs during the past six months. Twenty-two percent of participants reported drinking alcohol everyday during the previous six months, and 24% of participants said that they had put off going to HIV care because of being high on drugs and/or alcohol.

## Health system factors

More than one-fifth of respondents (21%) reported never having been to a doctor or clinic for HIV care. The majority of participants had received their initial HIV diagnosis more than five years prior to the baseline interview: 33% reported being diagnosed less than five years before the screening interview; 40% knew their diagnosis for more than five, but less than 16 years; and 26% reported they knew their HIV diagnosis for more than 16 years. In terms of assistance upon initial HIV diagnosis, 60% of participants reported being helped into HIV care, and 54% said they were initially referred to a case manager. Among the participants (75% of the cohort) who had a CD4 count recorded within 1 month of interview, the median CD4 count was 184 cells/uL and 54% had a CD4+ T-cell count below 200 cells/uL. Fewer than half (44%) of study participants were aware of their most recent CD4 count, while only 18% of participants knew their HIV-1 viral load. Approximately half (51%) of the study participants had been hospitalized at least one time in the 6 months prior to the interview. Most participants (70%) reported ever having gone to a drug or alcohol treatment program at some point in their life but only 18% had attended drug treatment during the previous six months.

## Bivariate analysis

The bivariate analysis for never having been in HIV care is presented in Table 2. Study participants who reported an annual income of less than \$5,000 were more likely to have never been to HIV care, as well as participants who were recruited at Grady Memorial Hospital in Atlanta. In terms of HIV history, participants who had been diagnosed within the past five years and who were not helped into care upon diagnosis were also more likely to have never been to HIV care. Participants who reported everyday use of crack cocaine within the previous six months had increased odds of never having been to HIV care, as well as those who had never injected drugs not prescribed by a doctor and those who had never participated in a drug treatment program.

## Multivariate analysis

Results of the logistic regression model for never having been in HIV care are presented in Table 3. Annual income served as the individual characteristic that was most significantly associated with never being in HIV care. Participants with annual incomes of less than \$5,000 had more than eight times higher adjusted odds of having never been to HIV care (adjOR, 8.17; 95% C.I., 3.35, 19.94). Health system factors including receipt of assistance into HIV care upon initial diagnosis, history of drug treatment, and hospital site (Atlanta vs. Miami) were also found to be significantly correlated with never having been to HIV care. Patients who were not helped into care upon their initial HIV diagnosis (adjOR, 2.83; 95% C.I., 1.56, 5.15) had increased odds of never having been to HIV care, as well as patients who had never participated in drug or alcohol treatment (adjOR, 4.13; 95% C.I., 2.24, 7.62). Finally, participants recruited from Grady Memorial Hospital in Atlanta had more than 2 times higher

adjusted odds of having never been to HIV care (adjOR, 2.57; 95% C.I., 1.36, 4.83). Variables including the Brief Symptom Inventory Depression scale, empowerment and social support were not found to be significantly associated with history of HIV care in the multivariate analysis.

## Discussion

The major finding of this study is that one fifth of our study sample of hospitalized HIV-infected crack users interviewed in Atlanta and Miami had never been to a doctor or clinic for HIV care. The study data suggest that individual background characteristics and health system factors each played a significant role in patients who reported never having been to HIV care. While the most significant individual characteristic in the study was income, there may also be other interrelated issues that reduce the likelihood that patients will go to HIV care. Income sources are very limited among this study population of HIV-infected crack users, as the majority of patients are unemployed and depend on monthly disability checks or drug-related exchanges for money. A major contributor to this socioeconomic instability is the constant cycle of crack cocaine use followed by drug-seeking activities, which can lead to poverty and homelessness. These living conditions have been reported in numerous studies as a barrier to utilization of HIV care and provide support for the development of housing or other structural interventions to improve the everyday lives of this population of persons living with HIV [21–23].

This study also suggests that health system factors were an important part of not seeking HIV care among HIV-infected crack users. For instance, a major predictor of never being in HIV care included not being helped into care by someone (social worker, counselor, family member, etc) upon initial HIV diagnosis. This result underscores the important role of social workers, counselors, and case managers to do active linkage to care for newly diagnosed HIV-infected patients to ensure that they are properly connected to HIV care and other necessary services such as drug treatment. Previous studies assessing delay in presentation to HIV care have demonstrated that social support and initial contact with newly diagnosed HIV persons by onsite clinical staff increase the likelihood of follow-up with HIV care [24–25]. For example, in the Antiretroviral Treatment Access Studies (ARTAS) study, a client-centered case management intervention significantly increased linkage to care for newly diagnosed HIV-infected patients [26].

The present study suggests that drug treatment is an important health system factor. HIV-infected crack users in Atlanta and Miami who did not have a history of drug treatment were four times more likely to have never been to HIV care. This finding supports previous data results indicating that substance abuse treatment is an important component of engaging in HIV care among HIV-infected drug users [27–28]. There are several possible explanations for the relation between drug treatment and entrance into HIV care. It is possible that study patients were helped into HIV care by their drug treatment program, especially if the program was associated with a primary care clinic. Patients who participated in a drug treatment program may have been more pro-active or physically able to address their health and substance abuse issues and therefore more likely to prioritize HIV care. This positive association between participation in a drug treatment program by HIV crack users and engagement in HIV care has been previously established by studies with inner city HIV patients [29]. Finally, the study analysis showed that participants recruited from Grady Memorial Hospital in Atlanta, GA were three times more likely to have never been to HIV care. Since both Grady Memorial Hospital and Jackson Memorial Hospital are major providers of HIV care in their regions and seem to have similar HIV epidemiology, it was not clear why the Atlanta study site was found to be a correlate for never having been to HIV care.



Some limitations of this study should be noted. First, these data are based on self-report. Although the data reported by participants during interviews were assumed to be correct, it is possible that the participants' report of their health, drug, sexual and psychosocial histories many have been limited by recall bias. Second, given the personal nature of the questionnaire and attention to sensitive topics such as HIV history, sexual practices and drug usage, participants might have underreported because of socially undesirable responses. However, in spite of this potential for bias, all research interviewers were able to conduct the study questionnaire objectively with each participant and did not report any deviations from protocol while administering the study questionnaire. Also, before enrolling all study participants the research interviewers took time to explain the personal nature of the questionnaire and the importance of patient privacy and confidentiality. This initial communication enabled the study participant and the research interviewer to establish a sense of trust and mutual understanding and helped the participants to feel more comfortable answering personal questions. The data analysis may have also been limited by factors or issues related to utilization of HIV care that were not covered by the study questionnaire. Although the structured study questionnaire was sufficient to document quantitative measures, it was limited in that it did not allow for unrestricted exploration of patient's histories and experiences that may provide additional explanation for failure to engage in HIV care. Finally, these data are from a sample of hospitalized HIV patients recruited from two Southeastern U.S. public hospitals in urban areas with predominantly African American patient populations; thus, generalizations to other HIV crack users in urban and rural areas or other countries should be approached with caution.

## Conclusions

Our study data highlight the fact that a substantial number of hospitalized HIV-infected patients interviewed in Atlanta and Miami are not connected to HIV care. Many of these patients are also actively using drugs, mainly crack cocaine and alcohol, are socioeconomically unstable, and present with low CD4 counts and have a history of recent hospitalization. These findings suggest that the hospital inpatient wards are a valuable setting for finding those patients who are not linked to care and intervening to facilitate linkage to care and prevention services. Novel models of outreach and social services that link HIV-infected crack users to regular HIV care upon discharge from the hospital may increase the likelihood that these patients will enter HIV care. Referrals to drug treatment, mental health and other social services by case managers will help ensure that the additional needs of HIV-infected crack users are addressed and may also improve their engagement in HIV care. From a prevention perspective, HIV-infected crack users engaged in care may benefit from patient-centered interventions that advocate reduction of high risk behaviors and promote access to HIV care, drug treatment, and social and mental health services. Finally, engagement of HIV-infected crack users in preventive HIV care services will be necessary to decrease the spread of HIV to their sexual partners.

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**Table 1**

Demographic and clinical characteristics of study participants. Values are frequencies with percentages in parentheses unless otherwise indicated.

<b>Characteristic</b>	<b>Value (N = 355)</b>
Female	186 (52%)
Age(years), (median, range)	43 (20 – 66)
African American	319 (90%)
Straight, heterosexual	286 (80%)
CD4+ lymphocyte count (cells/uL)	(N = 267)
< 200 cells/uL	144 (54%)
200 – 500 cells/uL	90 (34%)
>500 cells/uL	33 (12%)
Ever been to primary HIV care	282 (79%)
Been to primary HIV care in past 12 months	208 (59%)

**Table 2**

Variables Tested for Association with Participants' Reports of Never Having Seen an HIV Care Provider, from Bivariate Analyses 2006–2009

Characteristic (N = 355)	Total n (%)	Never in HIV Care (%)	P value
Male,	169 (47.6)	15.4	P = 0.021
Female	186 (52.4)	25.3	
Age			
< 40 years	93(26.2)	18.3	P = 0.526
≥ 40 years	262(73.8)	21.4	
City			
Atlanta	206 (58.0)	24.8	P = 0.022
Miami	149 (42.0)	14.8	
Yearly income			
< \$5000	233 (66.8)	27.9	P < 0.0001
≥ \$5000	116 (33.2)	6.0	
Time since HIV diagnosis			
≤ 5 years	108 (33.2)	42.6	P < 0.0001
6–10 years	64 (19.7)	1.6	
11–15 years	70 (21.5)	8.6	
16 – 20 years	53 (16.3)	15.1	
21 – 25 years	30 (9.2)	10.0	
AIDS diagnosis <sup>a</sup> within 1 month of baseline interview (N=308)			
Yes	116 (37.6)	26	P = 0.827
No	192 (62.3)	41	
Helped into care since HIV diagnosis			
No	142 (40.0)	31.7	P < 0.0001
Yes	213 (60.0)	13.2	
Frequency of crack use			
Everyday	118 (33.4)	32.2	P < 0.0001
Less than everyday	235 (66.6)	14.5	
Injection drug use, ever			
No	275 (77.5)	22.6	P = 0.023
Yes	79 (22.2)	12.7	
Drug Treatment, ever			
No	107 (30.3)	36.5	P < 0.0001
Yes	246 (69.7)	13.4	

<sup>a</sup> AIDS Diagnosis defined by CD4 count < 200 cells/mm<sup>3</sup> or AIDS defining illness [30].

**Table 3**

Adjusted Odds Ratios of Never Having Been to HIV Care, From Multiple Logistic Regression Analysis (N=349)

Variable	Adjusted Odds Ratio	95% CI
City (Atlanta)*	2.57	(1.36, 4.83)
Gender (Female)*	1.45	(0.79, 2.66)
Age (40 or older)*	1.07	(0.540, 2.12)
Annual income (\$5000 or less)	8.17	(3.35, 19.94)
No history of drug treatment	4.13	(2.24, 7.62)
Not helped into care upon HIV Diagnosis	2.83	(1.56, 5.15)

\* Forced into model.