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Vulnerabilities and caregiving in an ethnically diverse HIV population

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Abstract

The current study aimed to identify the primary informal caregivers of a group of urban HIV+ adults ($n = 250$) and to determine relationships between demographic, medical, and substance use characteristics and caregivers types. Reported caregiver types included 36.8% familial, 22.4% significant other, and 22.8% institutional or other caregiver relationships. The remaining 18% of the sample reported having no individual that rendered informal care. Factors associated with the absence of an informal caregiver included African American race and low education. Hispanic participants reported the highest frequency of family caregivers while participants with a history of substance disorder were less likely to identify a significant other as a caregiver. This study demonstrates the evolving nature of informal caregiving in HIV, race- and education-related disparities in the absence of primary caregivers, and the importance of sociocultural and demographic factors in the study of HIV caregiving.

Keywords

Social support; Caregiving; Psychosocial; HIV; Ethnic minorities

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Introduction

Informal caregiving became a standard element of HIV/AIDS care during the first decade of the epidemic. The context of informal care in this disease was unique in comparison to the caregiving relationships of other chronically ill persons because persons infected with HIV in the US, at the outset, were characterized as young, male, and homosexual (Wardlaw 1994; Zarit et al. 1993). Much of the prior research on HIV caregiving identified caregivers as friends, neighbors, same-sex partners, and co-workers within a White, middle-class, and self-selected framework (Turner et al. 1994, 1998). As the HIV epidemic expanded to encompass significantly more racial and ethnic minorities, so have the social structures, including social supports that provide informal care. However, potential changes in caregiving practices as a result of the shift of HIV to a racially disparate disease, have not been fully explored. As such, there is a paucity of research on caregiving practices within ethnically diverse HIV cohorts with vulnerable characteristics (e.g., advanced disease, limited financial resources, comorbid psychiatric and substance use disorders, and low education). Knowledge of the nuances of informal care practices in this population is essential for a comprehensive understanding of HIV caregiving and has implications for the development of targeted adherence interventions.

The challenges of providing informal care to persons infected with HIV/AIDS have been well documented over the past two decades. In the post-HAART era, HIV service delivery systems shifted from acute care to chronic disease treatment, increasing the need for formal and informal care (Matheny et al. 1997; Silverman 1993). Informal caregivers are often non-professional volunteers who provide essential services individually or as part of a community network (Matheny et al. 1997). In the HIV caregiving literature, prior studies have identified same sex partners, friends, distant relatives, significant others, and close family members as primary informal caregivers. Additionally, younger individuals and men are highly likely to be identified as caregivers in the HIV literature (Levin et al. 2005; Pearlin et al. 1994; Turner et al. 1998; Wrubel and Folkman 1997). This is in contrast to typical caregiving paradigms, such as those for Alzheimer's disease, where care is typically provided by one's family of origin, blood relation kin, or significant others. Age and gender are consistent correlates across traditional caregiving studies with women and older individuals providing the majority of care (Dilworth-Anderson et al. 1999; Keith 1995; Marks 1996). These varied caregiver profiles across populations make the issue of HIV caregiving in American ethnic minorities anomalous and worthy of independent analyses.

The current HIV caregiving literature is largely based on the experience of gay, economically resourceful, socially connected White males. With over 50% of new cases of HIV being diagnosed in racial and ethnic minorities, many of the prior studies lack generalizability to the current face of HIV (CDC 2004). The limited studies that attempt to capture the experience of minority HIV populations document a pattern among African Americans of seeking help for non-critical problems from close relatives with similar lifestyles and resources (Gant 1996; Knowlton 2003; Neighbors 1990). Typically, the literature presents African Americans and Hispanics as more inclined to participate in informal caregiving in comparison to Whites (Gant 1996; Turner et al. 1994). Researchers have attributed these findings to socioeconomics and cultural values (Neighbors et al. 1998; Williams and Jackson 2005). For example, the literature highlights the role of *familismo* in the preponderance of familial caretakers among Hispanics. *Familismo* refers to the strong emphasis placed on the importance of the family as the center of one's experience (Depp et al. 2005). Similarly, African Americans often report filial responsibility as a motivation for providing informal care and the sick and elderly in African Americans often reside in homes with extended family members who provide care (Cox 1993; Dilworth-Anderson et al. 2005). However, these findings do not take into account the stigmatization of HIV in ethnic minority communities resulting from the mode of HIV transmission as well as other factors, i.e., substance use or maladaptive behavior, that continue to negatively impact social ties that underlie social support.

The mode of transmission of the disease may influence whether or not one's family of origin is actively involved in care, especially in the case of substance users and homosexuals. There are numerous studies that document the nontraditional care structures organized in the wake of HIV in gay communities (Folkman et al. 1994; Irving et al. 1995; Land et al. 2003; Levin et al. 2005; Turner et al. 1998; Wight et al. 2003). Similarly, past and current substance use, specifically injection drug use, has been shown to have the same distancing effect on the family of origin and significant others (Knowlton 2003). Families often will reject the drug user and, even after abstinence, reintegrating into the family or community can be difficult for the infected person (Crystal 1992). Johnston et al. (1995) found that HIV infected injection drug users and homosexuals reported similar patterns of social support with more support from friends than family. Perhaps the most remarkable finding of these studies is the consistency of participants' report of low-levels of social support, which coincided with declines in health.

The negative health consequences of intravenous substance use on individuals with HIV has been well documented and include the inability to sustain social support networks that foster positive health outcomes (Celentano et al. 1998; Knowlton et al. 2005; Latkin et al. 2004). Level of social support has also been shown to be a significant predictor of HIV disease progression with lower levels of social support paralleling lower CD4 counts and inversely affecting disease progression (Theorell et al. 1995; Young et al. 2004). Likewise, in a group of Spanish-speaking Hispanics, having emotional and informational support was associated with increased HAART adherence (Servellen and Lombardi 2005). When mental illness is taken into account, disorders such as depression and substance use negatively impact medication adherence as well as social support (Broers et al. 1994; Catz et al. 2000; Lucas et al. 1999; Reynolds et al. 2004). Other factors that may modify social support are psychosocial and biologic correlates such as education level and severity of illness.

Research on the impact of education on caregiving practices in HIV has produced equivocal results. In the pre-HAART HIV caregiving literature, studies conducted with primarily White males often predicted that higher education levels was associated with the presence of significant other caregivers (Graham et al. 1994, 1991). However, in the post-HAART era, Silver et al. (2003) found that HIV+ women with lower education received more social support than HIV+ women with more educational attainment and fewer disease symptoms. In this study, the author reported that more support was provided to women who reported a high number of physical illness symptoms. In the general caregiving literature, care is often provided for individuals who become increasingly ill or who lack the ability to take care of instrumental tasks on their own. Rarely discussed in the literature are individuals with advanced HIV and diffuse social and health challenges that report not having a caregiver or lack any supportive network. Although there are studies that identify factors that may influence social support, there are limited studies that examine caregiving practices within diverse medically fragile populations (Berkman 1995; Brummett et al. 2001).

The current study had two primary aims: (1) to identify the caregivers of a large group of urban, ethnically diverse advanced HIV infected recipients of care in New York City; and (2) to determine relationships between these individual's demographic, medical, characteristics, and type of identified caregiver. We sought to determine whether findings of other research studies of caregiving types in HIV would be replicated in a group of HIV infected participants who displayed a high prevalence of other serious factors known to impact levels of psychosocial support. Based upon the existing literature on HIV caregiving, we hypothesized that: (1) Ethnic and racial minorities would identify a larger proportion of familial caregivers than White participants; (2) Demographic and medical characteristics (i.e., gender, age, education, and level of illness) would be related to caregiver type; (3) Individuals who identified homosexual sex as a risk factor for HIV would be less likely to identify family members as caregivers; and (4) Individuals with current or past substance use histories would be less likely to identify family or significant others as caregivers when compared to those without substance use histories.

Method

Overview

The data presented are from the Manhattan HIV Brain Bank (MHBB; R25MH59724), funded by the National Institutes of Health. The MHBB is a longitudinal observational and tissue donation study that includes biannual neurological, neuropsychological, medical, and psychiatric evaluations of adults with late stage HIV.

Participants

A total of 250 participants enrolled in the MHBB between 1998 and 2005 were selected for this study based upon completed baseline assessments. All participants were HIV-infected and gave consent for post-mortem organ donation for research purposes. MHBB eligibility criteria have been published previously (Morgello et al. 2004) and include: (1) the presence of a condition indicative of advanced HIV or without effective therapy; (2) CD4 count ≤50 cells/mm^3 for at least 3 months, or (3) substantive risk for imminent mortality in the judgment of the participant's primary physician. Patients with active psychosis were excluded. For this substudy, data from baseline evaluations were utilized.

Procedure

All participants completed comprehensive neuromedical, psychiatric/substance use and neuropsychological evaluations. The clinical interview included a detailed demographic questionnaire, which queried education, HIV risk factors (i.e., homosexual sex, heterosexual sex, intravenous drug use, other or exposure unknown), and presence and type of social support. Information on education level was not available for two participants.

The participant's estimated income was evaluated using median income for each participant's respective zip code as indicated by the 2000 US Census data (US Census Bureau 2000).

Measures

Substance Use Disorders—The Psychiatric Research Interview for Substance and Mental Disorders (PRISM) was used to assess the presence of psychiatric and substance use disorders according to DSM-IV criteria (Hasin et al. 1996). The PRISM is a semistructured professional psychiatric interview that allows the examiner to diagnose disorders occurring within the past 12 months of study entry (“current”), as well as “past” disorders, those occurring prior to the last 12 months. While several subsections of the PRISM were administered, only the Alcohol and Drug Use subsections were utilized for the present study. The substance disorders included abuse and dependency for: alcohol, cocaine, opiates, stimulants, sedatives/hypnotics, hallucinogens, cannabis, and “other” substances.

Caregiving Assessment—During the clinical intake interview, participants were asked to identify a primary informal caregiver and to briefly describe their relationship to this person. This caregiver, if such a person existed, was defined as being an individual who was not part of the participant's medical care team, and who would assist the participant in the event of incapacity or illness in supportive functions. For example, participants were asked questions such as “If you were sick in bed at home, who would take care of you?” or “If you were sick, who would do your shopping or cook you chicken soup?” Based on participant self report, caregiver relationships were initially organized into 13 categories: children over 21, grandchildren over 21, grandparents, parents, siblings over 21, family, common-law spouse, same sex partner, legal spouse, institutional, other, friend, and none. Spouse was defined as per the New York State 1998 definition of opposite sex legally recognized unions. The category “institutional” was chosen when the participant could not identify an individual who offered informal caregiving, but resided in a long term care facility which assumed informal caregiving roles. The category NONE was assigned to individuals who did not reside in long term care facilities, and who could not identify any non-medical individual who provided informal caregiving or support. These initial categories where then organized into four groups for the purposes of analysis: FAMILY (children over 21, grandchildren over 21, grandparents, parents, siblings over 21, other blooded family); SIGNIFICANT OTHERS (common-law spouse, same sex partner, legal spouse); OTHER (institutional, other, friend); and NONE.

Disease Markers—Blood samples were obtained during the neuromedical assessment. As indicators of HIV disease status, CD4 cell count (cells/mm^3) and HIV viral load (copies/ml) were determined either by review of the medical record, or if not available, by study laboratory run on these samples.

Statistical Analysis—To determine the associations between participant characteristics and caregiver type, chi-squared tests and independent *t*-tests were utilized. Caregiving groups were condensed into the four categories described above (FAMILY, SIGNIFICANT OTHERS, OTHER, and NONE) for use in analyses. Age was dichotomized at 50 years for some analyses, which is consistent with prior studies of aging and HIV (Casau 2005; Nichols et al. 2002). Values for plasma viral load were $\log_{10}$ transformed prior to use in statistical analysis.

Logistic regression analyses were conducted to determine the predictive value of demographic factors to caregiver group membership. For these analyses age and education were entered as continuous variables while race (dummy coded with Whites as the reference group) and gender were categorical. Odds ratios and 95% confidence intervals were computed for each variable included in the models. A hierarchical multiple regression was performed to examine the association between demographic characteristics, caregiver type and disease severity (CD4 count).

Results

The sample included 250 individuals enrolled in the MHBB (75% male; see Table 1). Participant's mean age was 44.8 years (SD = 7.8), and mean education level was 12.3 years (SD = 2.9). Of note, almost 40% of the sample did not complete high school. The median estimated neighborhood level income for the sample was $25,236. The group was 46% African American, 28% Hispanic and 25% Non-Hispanic White. Median CD4 count was 116 cells/mm^3 ($M = 233$ cells/mm^3, SD = 299); median $\log_{10}$ plasma viral load was 3.76 copies/ml ($M = 3.61$ copies/ml, SD = 1.48).

Caregiving Relationships

The largest category of primary caregiver identified by study participants was FAMILY (36.8%; see Table 2). The next most frequently reported caregiver types were OTHER and

SIGNIFICANT OTHER, respectively. “NONE” was a category created to capture the caregiving experience of individuals who reported not having any social support; 18% of study participants reported not having any caregiver at all. About 64% of the primary caregivers were female when the NONE and INSTITUTIONAL categories were not considered in the calculation.

Participant Characteristics and Caregiving

Several bivariate and multivariate analyses were conducted to determine the relationships between participant demographic characteristics and caregiver type (see Table 3). Consistent with our hypothesis, Hispanics reported greater frequency of FAMILY caregivers (47%) than African Americans (34%; χ^2 (1) = 2.92, $P < .10$) and Caucasians (32%; χ^2 (1) = 3.03, $P < .10$), though these differences did not reach statistical significance. However, African Americans reported similar frequencies of FAMILY members as caregivers as White participants (χ^2 (1) = .09, $P > .05$). White participants reported significantly more OTHER caregiving relationships (32%) than Hispanics (16%; χ^2 (1) = 4.96, $P < .05$) but not African Americans (23% χ^2 (1) = 1.77 $P >.05$). SIGNIFICANT OTHER relationships were similar between Whites and African Americans (χ^2 (1) = 1.47, $P >.05$) and Whites and Hispanics (χ^2 (1) = .61, $P > .05$). The frequency of SIGNIFICANT OTHER (χ^2 (1) = .61, $P >.05$) and OTHER (χ^2 (1) = 1.39, $P > .05$) caregiver relationships was not significantly different between Hispanics and African Americans. African American participants were more likely to endorse not having any caregiver at all, relative to other racial/ethnic groups (24% vs. 10% for Whites and 14% for Hispanics; χ^2 (3) = 11.51, $P < .01$).

The influence of participant gender on identifying caregiver type and caregiver gender was also evaluated with chisquare analyses. No unique patterns of caregiving were observed for male and female study participants (χ^2 (3) = .36, $P > .05$). Similarly, participant gender was not preferentially associated with caregiver gender (χ^2 (1) = 3.74, $P >.05$).

Education associations were initially analyzed in a bivariate fashion (high school versus less than high school) with caregiver type. Participants with less than a high school education were more likely to report NONE and FAMILY (χ^2 (3) = 3.76, $P <.05$) as caregivers. Additionally, this group was less likely to identify SIGNIFICANT OTHER caregivers (χ^2 (3) = 3.23, $P <.05$).

Study participants who were 50 years of age or older, when compared to younger participants, did not demonstrate significantly different caregiver relationships (χ^2 (3) = 3.42, $P > .05$). When the data were analyzed according to primary HIV risk factor, homosexual sex risk was associated with a slightly increased likelihood to identify SIGNIFICANT OTHERS as caregivers (χ^2 (1) = 3.16, $P <.10$) and a slightly decreased likelihood to report FAMILY members as caregivers (χ^2 (1) = 3.16, $P < .10$), when contrasted with intravenous drug use and heterosexual risk groups.

Substance Use

About 80% of the total sample reported having a past substance use disorder and 30% met DSM-IV criteria for a current disorder. In concordance with our hypotheses, participants with a past (χ^2 (1) = 11.14, $P < .01$) or current (χ^2 (1) = 10.91, $P < .01$) history of a substance disorder were less likely to identify a SIGNIFICANT OTHER as a caregiver. With respect to the hypothesized increased familial caregiving presence for persons with substance use histories, the same did not hold true; there was no significant association between past (χ^2 (1) = .21, $P > .05$) or current (χ^2 (1) = 1.95, $P > .05$) substance use and FAMILY caregivers.

Participants with No Caregiver

Given the unexpected proportion of participants who were unable to identify a primary caregiver, this group of individuals was examined more closely. We found that those who identified "NONE" to be similar in age ($t(248) = -.95$, $P > .05$), gender ($\chi^2(1) = .11$ $P > .05$), and substance use histories ($\chi^2(1) = 2.71$, $P > .05$) to the remaining sample who had identified a primary caregiver (see Table 4). However, as stated above, African American participants were more likely to endorse not having a caregiver ($\chi^2(3) = 11.5$, $P < .01$). Consistent with bivariate analyses of education (high school graduate versus less than high school), an examination of differences in number of years of education revealed that participants without a caregiver completed fewer years of education ($M = 11.4$ years) than those with definite caregiver relationships ($M = 12.5$; $t(243) = 2.32$, $P < .05$). With regard to biomarkers of HIV disease, participants without primary caregivers had lower CD4 counts than other study participants ($t(231) = 2.86$, $P < .05$), though the two groups did not significantly differ on mean plasma HIV load ($t(228) = 1.36$, $P > .05$).

Modeling Caregiver Group Membership

Table 5 presents the results of four logistic regression analyses to determine the value of demographics factors: race, age, years of education, and gender, in the prediction of membership in each caregiver category. The models for FAMILY and OTHER caregiving relationships were not significant, ($\chi^2(5) = 8.78$, $P > .05$) and ($\chi^2(5) = 9.79$, $P > .05$), respectively. The third model, predicting membership in the SIGNIFICANT OTHER caregiver category, was statistically significant, ($\chi^2(5) = 16.37$, $P < .01$). Of the predictors included in this model, only education was significantly associated with the SIGNIFICANT OTHER outcome. Every standard deviation increase in education (i.e., 2.9 years) was associated with a 12.30 times greater chance of reporting a Significant Other as primary caregiver. The model for membership in the NO Caregiver group approached significance ($\chi^2(5) = 10.87$, $P > .05$). Education was the only individual predictor significantly associated with having no caregiver when all predictors were entered.

Every standard deviation decrease in education was associated with an 8.79 increase in the chance of not having a caregiver.

Caregiver Type and Illness Severity

ANOVA analyses revealed that participants with SIGNIFICANT OTHERS as caregivers had significantly higher CD4 count and those with NONE had significantly lower CD4 count than each other caregiver group ($F(3, 231) = 3.46$, $P < .05$). No other significant differences emerged from comparisons of CD4 count of other caregiving groups. No significant differences were observed between caregiving groups on plasma viral load ($F(3, 226) = 1.32$, $P > .05$). Therefore, CD4 count was selected for additional biologic outcomes analyses. Hierarchical regression was used to examine the caregiving factors associated with illness severity (CD4 count). Potential demographic confounds (age, education, gender, race) were entered at step 1. Older age and African American race were significantly associated with lower CD4 count (see Table 6). Of the caregiver types, entered at the second step of the model, membership in the NO CAREGIVER group was also associated with lower CD4 count. The full model accounted for 15% of the total variance in CD4 count.

Discussion

The transition of HIV infection to a chronic illness that requires strict adherence to medication regimens necessitates greater attention to the role of informal caregiving in the conceptualization of disease management. Results of the current study indicate that overall, urban, ethnically diverse individuals with advanced HIV present with a varied profile of primary informal caregivers, with a surprisingly high proportion reporting not having a primary caregiver at all. This examination of the nature and sociocultural contexts of care patterns in HIV+ ethnic minorities is among the first to uncover race and education-related disparities in HIV caregiving.

Bivariate analyses of the data revealed unique racerelated patterns in types of caregiving relationships. Unexpectedly, African American participants did not endorse a high proportion of family caregivers, suggesting that documented illness-related stigma may continue to impact family-based HIV care in this population (Gant 1996; Willams and Jackson 2005). However, almost half of all Hispanic participants identified a family member as a primary caregiver, which is consistent with the literature describing Hispanic families as highly supportive and loyal (Sabogal et al. 1987). This finding suggests that common cultural values like *familismo* and collectivism, may have influenced Hispanic caregiving practices and that these values, through their impact on caregiving, could contribute to the favorable health outcomes documented in this group in spite of unfavorable social conditions, the “Hispanic paradox” (Markides and Eschbach 2005; Soriano 1991). Additionally, acculturation may play a significant role in the expression of these cultural values and, when paired with silence regarding sexuality and substance use within Hispanic communities, may outweigh stigmatization in the decision to provide family support to HIV infected loved ones (Pearlin et al. 1994). On the contrary, White participants, who in our sample were more likely to be homosexual, may have access to wider support networks and participate openly in gay communities where care is provided by friends or other associates (Pearlin et al. 1994; Turner et al. 1994). Thus, White participants were more likely to identify “Other” caregivers in our study, which included friends and neighbors. Similarly, we observed that participants with a homosexual risk factor for HIV, irrespective of race, were more likely to endorse “Significant others” as caregivers.

Contrary to research with other cohorts, the only demographic characteristics that influenced caregiving patterns in our population were education and race. Age and gender, while supported in the literature as predictors of the presence and type of caregiving in other groups, were not associated with caregiving types in the current study (Dilworth-Anderson et al. 1999; Keith 1995; Marks 1996). It is possible that in urban cohorts, these factors are less salient than race and poor quality of education, which could emerge as primary determinants of care via limited access to resourceful social support networks. A more detailed, prospective study of caregiving patterns in HIV might reveal that demographic factors have tiered importance levels, with education and race operating as initial determinants, and age and gender gaining importance as secondary factors.

Participants with past or current substance use disorders were less likely to have a spouse, same-sex partner, or other intimate relation as a caregiver. One explanation for this could be the impact of substance use on intimate social support mechanisms. For example, family relationships tend to be non-volitional and “automatic,” while friendships and intimate relationships with significant others are more susceptible to conflict and resulting choice not to provide care when a partner is abusing illicit substances. Thus, histories of substance abuse may place HIV+ persons at risk for disrupted intimate relations and cause these persons to look to other sources for caregiving.

In this study, a surprising 18% of participants reported not having any informal caregiver at all. Our study is unique in its focus on isolating and describing this overlooked group. Bivariate analyses revealed that African American race, low education, and low CD4 count were associated with membership in this group. These factors represent major vulnerabilities for poor HIV care. Given the overrepresentation of African Americans in the “No caregiver” group, these findings add a new dimension to existing literature in other illness paradigms which suggest that informal caregiving is “normative” among this ethnic group (Dilworth-Anderson, et al. 2005; Gant 1996). Our study indicates that the existing literature cannot solely explain patterns of caretaking for HIV+ African Americans. This race/ethnicity-related disparity may be a reflection of the ongoing stigmatization of HIV within the African American community. Victim-blaming and discrimination of people living with HIV within this community, due largely to the taboo nature of male homosexuality and the association of the disease with illicit substance use, are well-documented in the HIV literature (Gant 1996; Poindexter and Linsk 1999).

In contrast, multivariate analyses of predictors of membership in the “No caregiver” group revealed that when demographic factors were considered simultaneously, the impact of low education outweighed African American race and was the sole significant predictor in the model. This finding indicates that low levels of education, regardless of racial/ethnic background, places persons infected with HIV at risk for not having solidified caregiving relationships. The apparent salience of low education for caregiving cannot be overlooked. Though the findings require replication, they underscore the importance of the inclusion of marginalized populations in the study of HIV caregiving. The observational nature of the current study prevented a full exploration of specific aspects of low education that could account for the relationship (i.e., poverty, limited coping mechanisms, overburdened social networks, etc.). Whatever the basis of this phenomenon may be, there are limited studies that describe or examine the lack of an informal caregiver or support network within the HIV population. The few studies that allude to this subject matter are clinical observations which examined the impact of social support structures on the progression of HIV (Knowlton et al. 2005; Theorell et al. 1995). In this context, it is important to consider results from our study of caregiving predictors of biologic outcome in HIV.

Our study demonstrated that illness severity, as measured by CD4 count, could be predicted, in part, by the type of caregiver support received by participants. Higher CD4 counts were associated with “Significant Other” caregiving relationships. The presence of primary and consistent support from a significant other may indirectly increase treatment adherence and other healthy behaviors more than support from family or friends. It is also possible that the ability to maintain an intimate relationship could indirectly improve health through reduction of depressive symptoms or self-destructive behaviors. Alternatively, low CD4 counts were predicted by older age, African American race, and membership in the “No caregiver” category, suggesting, that the absence of a caregiver, in conjunction with older age and African American race places persons with HIV at particular risk for greater illness severity. Indeed, numerous studies show that having a steady and consistent social support network is correlated with positive health outcomes in HIV (Brummett et al. 2001; Theorell et al. 1995). However, the cross-sectional design of the current study prevented the ability to make causal inferences between biologic outcome and caregiving types. Nonetheless, these findings demonstrate the importance of consideration of the health and well-being of persons infected with HIV when examining caregiving patterns and in designing treatment adherence interventions.

The perfect model has yet to be created that accounts for all of the sociologic, behavioral, and environmental influences that poor, low education and HIV-infected individuals are subject to on a daily basis. Thus, the channels and levels of informal care are yet to be clearly identified and understood for this population. The current study demonstrates the unusual and nuanced patterns of caregiving within a vulnerable population. The few studies that have been conducted in similar populations show that informal caregiving is affected by social relationships and economic resources. Specifically, individuals within these populations tend to rely on others who share similar burdens and/or comorbidities, leading them to seek help from others with similar health profiles and limited resources (Knowlton

2003; Silver et al. 2003). At this time, these available findings are limited and isolated and not yet able to be woven into a larger theoretical framework.

There are a variety of limitations inherent in this initial pilot observational study. First, there was an exclusive focus on the identification of primary caregivers with no attention to clusters of caregivers. We also did not systematically record the types and frequency of care that caregivers actually provided (i.e., daily instrumental support, occasional basic support, etc.). Additionally, we did not analyze the specific types of substance addictions and mental disorders present in the population, to ascertain if any particular psychiatric disease constellation predicted absence of informal care. Future studies that address these limitations can greatly advance the understanding of HIV caregiving in vulnerable populations.

Finally, the unique findings from the current study uncover a large knowledge gap in the literature on the nature of modern HIV caregiving. Most important was the identification of education and racial disparities in HIV caregiving: persons with less education or who were African American were most likely to not have an identified caregiver. Our results also highlight the importance of consideration of the interplay of caregiving factors and biologic endpoints in HIV disease. Given the observational nature of this study, replication in other urban cohorts is necessary. Future studies will also be warranted to derive a more complete understanding of the factors that influence informal caregiving networks in urban, minority populations with advanced HIV.

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Table 1

Study participants' characteristics

Variable	***n***	**Percentage**
Gender		
Male	184	74.6
Ethnicity	115	46
African–American		
Caucasian	63	25.2
Hispanic	71	28.4
Other	1	0.4
Education	M = 12.3 (SD = 2.9) Mdn = 12	
Less than high school	98	39.2
High school	49	19.6
Some college	59	23.6
College degree/Graduate studies	39	15.6
Income[a]	187	
Less than $19,100	52	20.8
$19,135–$25,236	45	18
$25,458–$38,917	47	18.8
$39,614 and above	43	17.2
Identified risk factors		
Homosexual contact	74	29.6
Heterosexual contact	68	27.2
IVDU	72	28.8
Homosexual contact and IDU	13	5.2
Other or unknown	23	9.2
Current substance disorder	76	30.4
Past substance disorder	200	80

IVDU = Intravenous drug use

[a] Estimated from median neighborhood income; Individuals residing in long term care facilities excluded

Table 2

Primary caregiver characteristics

Variable	*n*	Percentage
Caregiver gender[a]		
Female	121	64
Caregiving groups		
Family	92	36.8
Parents	35	14.0
Siblings over 21	31	12.4
Children over 21	17	6.8
Other family	5	2.0
Grandparents	3	1.2
Grandchildren over 21	1	0.4
Significant other	56	22.4
Same-sex partner	28	11.2
Spouse	16	6.4
Common-law spouse	12	4.8
Other	57	22.8
Friend	29	11.6
Institutional	16	6.4
Other	12	4.8
None	45	18

[a] Information on caregiver gender was available for 195 participants

Table 3
Participant characteristics and caregiving

Variable	Caregiver type percentage			
	Family	Significant other	Other	None
Ethnicity				
African–American[a]	34	19	23	24**
White	31	27	32	10
Hispanic[b]	47*	24	15	14
Education				
High school and above	32**	30**	25	13**
Less than high school	45	11	19	25
Risk Factor[e]				
Homosexual sex[c]	27*	30*	24	19
Heterosexual sex	43	13	22	22
IVDU	39	21	21	19
IVDU and Homosexual	46	15	39	0
None and other risk	39	35	17	9
Substance use				
Past substance use	38	18**	24	20
Current substance use	43	9**	24	24
No history of substance use[d]	34	40	16	10

IVDU = Intravenous drug use

** $P<.05$

* $P<.10$

[a] African–American > Hispanic, White with regard to having no caregiver

[b] Hispanic > African–American, White with regard to identifying a family member as primary caregiver

[c] Homosexual risk versus Heterosexual, IVDU, IVDU/Homosexual risk groups; greater percentage identifying a significant other and fewer identifying a family member as their primary caregiver

[d] Individuals without a history of substance abuse more likely to report significant other as primary caregiver than those with past or current history of substance use syndrome

[e] Categories not mutually exclusive

Table 4

Characteristics of participants with and without caregivers

Variable	**With caregiver *n* = 205**		**Without caregiver *n* = 45**	
	M	**SD**	**M**	**SD**
Age	44.6	7.8	45.8	7.9
Education [*]	12.5	3.0	11.4	2.6
CD4 count [*] (cells/mm^3)	251.7	311.9	111.9	219.7
Viral load	3.54	1.5	3.89	1.4
	n	%	*n*	%
Gender (Males)	150	74	34	76
Race/Ethnicity [*a]				
African–American	87	76	28	24
Hispanic	61	86	10	14
White	57	91	6	9
Other		0	1	2
History of substance use	160	78	40	89
Current substance use	58	29	18	42

[*] $P < .05$

[a] Greater representation of African–Americans in the no caregiver group than other races/ethnicities

Table 5

Logistic regression analyses of demographic predictors of caregiver relationships

Predictor	β	SE	Odds ratio	95% CI	
				Lower	Upper
Family					
African–American ethnicity	−.108	.357	.898	.446	1.80
Hispanic ethnicity	.468	.383	1.60	.753	3.38
Age	−.002	.018	.998	.964	1.03
Education	−.095	.050	.910	.824	1.04
Gender	.153	.307	1.17	.639	2.13
χ^2 (5) = 8.78, $P > .05$ Other					
African–American ethnicity	−.342	.380	.710	.337	1.49
Hispanic ethnicity	−1.06	.470	.345	.137	.868
Age	−.037	.021	.963	.925	1.00
Education	.046	.058	1.05	.935	1.17
Gender	−.124	.370	.883	.428	1.82
χ^2 (5) = 9.79, $P > .05$ Significant other					
African–American ethnicity	.066	.420	1.07	.469	2.43
Hispanic Ethnicity	.513	.450	1.67	.692	4.03
Age	.025	.021	1.03	.984	1.07
Education[*]	.207	.064	1.23	1.09	1.39
Gender	.268	.367	1.31	.638	2.68
χ^2 (5) = 16.37, $P < .01$ No caregiver					
African–American ethnicity	.718	.481	2.05	.799	5.25
Hispanic ethnicity	.022	.563	1.02	.339	3.08
Age	.019	.023	1.01	.975	1.066
Education[*]	−.130	.064	.879	.775	.996
Gender	−.340	.404	.712	.322	1.57
χ^2 (5) = 10.87, $P < .05$					

[*] $P < .05$

Table 6

Hierarchical multiple regression predicting CD4 count

Independent variables	*B*	*β*	R^2	R^2ΔChange
Step 1: Demographic controls			.136 *	
Age	11.37	.304 **		
Education	4.17	.042		
Gender	21.64	.033		
African–American[a]	−119.52	−.204 *		
Hispanic[a]	−84.31	−.129		
Step 2: Caregiver group membership[b]			.180 **	.044 **
Significant other	71.82	.102		
Other	−24.04	−.034		
None	−125.95	−.167 *		

[a] White was the contrast ethnic group

[b] Family was the contrast caregiver group

* $P < .05$

** $P < .01$