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Caregivers' support network characteristics associated with viral suppression among HIV care recipients

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Abstract

Informal care receipt is associated with health outcomes among people living with HIV. Less is known about how caregivers' own social support may affect their care recipient's health. We examined associations between network characteristics of informal caregivers and HIV viral suppression among former or current drug using care recipients. We analyzed data from 258 caregiver-recipient dyads from the Beacon study, of whom 89% of caregivers were African American and 59% were female. In adjusted logistic regression analysis, care recipients had lower odds of being virally suppressed if their caregiver was female, was caring for youth involved in the criminal justice system, and had network members who used illicit drugs. Caregivers' greater numbers of non-kin in their support network was positively associated with viral suppression among care recipients. The findings reveal contextual factors affecting ART outcomes and the need for interventions to support caregivers, especially HIV caregiving women with high-risk youth.

INTRODUCTION

In the United States, only 30% of the 1.2 million people living with HIV (PLHIV) have successfully navigated the HIV care continuum and are virally suppressed (1). Racial disparities in HIV diagnosis and achieving viral suppression are well documented, including differential access to care and treatment (1). African Americans, compared to other racial/ethnic groups, are disproportionately infected with HIV, less likely to have access to care

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Compliance with Ethical Standards

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent: Informed consent was obtained from all individual participants included in the study.

Conflict of interest: The authors declare that they have no conflict of interest

and adhere to antiretroviral therapy (ART), and experience higher rates of morbidity and mortality (1–3).

In Baltimore City, Maryland, the majority of the population is African American and the vast majority of PLHIV, including new HIV cases, are among African Americans (4). HIV is one of many challenges facing Baltimore, a city with a poverty rate that exceeds the national average, with 24% of residents living below the poverty line (5). Baltimore City also has high rates of heroin, cocaine and substance abuse; by one estimate 1 in 8 adults needs substance use treatment (6). Baltimore also has an incarceration rate that is three times the national average and PLHIV with an incarceration history experience gaps in ART and health care access both within prisons and when they reintegrate into communities (7–10). It is within this context of high levels of poverty, incarceration and substance use disorders that PLHIV in Baltimore and their informal caregivers are living with and managing HIV and other often highly stigmatized chronic conditions.

Informal caregiving and HIV outcomes among PLHIV

Research has found that among PLHIV, African Americans and persons with a drug use history are less likely to have informal care, and that low-income African Americans provide more labor-intensive forms of informal care compared to other racial/ethnic groups (11). Informal caregiving is often defined as emotional or instrumental assistance by unpaid partners, family members or friends, to someone with a serious health condition (12, 13, 14). Caregivers are thought to affect recipients' medical care and treatment adherence through direct instrumental assistance (e.g. assisting with medications, clinic visits), or indirectly by either promoting routines and norms that facilitate adherence or by buffering the effects of depression, substance use, stress, or other impediments to adherence (15,16). A multisite study conducted in the United States of PLHIV who use drugs found that the odds of achieving or maintaining viral suppression was 4.6 times greater among those with informal care compared to those without informal care (17).

Caregiving is often stressful, particularly in highly stigmatized and late stage illnesses, and social and emotional support has been found to be critical to caregivers' well-being and care provision (18, 19). At the same time, prior research has found that African Americans and caregivers of PLHIV tend to have low levels of social support compared to other racial/ethnic groups or caregiving populations, potentially due to the challenges faced with stigma, drug use, poverty, and competing caregiving demands (20–22). This lack of social support may also be the cause or consequence of caregiver burden: the negative psychological, behavioral, and physiological effects of caregiving on the daily lives of caregivers (22–26). The demands of caregiving may interfere with caregivers' family, work and leisure activities, which then leads to strained social relationships, social isolation, depression, and/or other adverse consequences (20, 22, 27, 28). Women, particularly low-income African American women, are more likely than men to be caregivers and to have multiple caregiving responsibilities, including care for children and other family members (29). For caregivers, raising youth involved in the legal justice system may compound caregiving burden (30), especially in communities with high prevalence of drug use, incarceration and family disruption. Furthermore, caregivers' greater number of current drug users in their support

networks has been found to be negatively associated with viral suppression among PLHIV care recipients in Baltimore (18). Moreover, social support networks have the potential to mitigate caregiver burden and stress, and reduce caregiver depression that is often related to the cessation of informal caregiving (20, 26, 28). On the other hand, caregiver networks may also be a source of stress or obligation that affects the quality and type of HIV care the caregiver is able to provide. It is generally accepted that support networks may directly impact the health and wellbeing of someone living with a chronic illness. These previous studies described above, combined with the literature on social support (31), however, highlight the potential importance that the caregiver's networks may have on the provision of care by informal caregivers and ultimately the HIV-related health outcomes of PLHIV.

Synthesis and purpose

Caregiving research has historically examined how the individual characteristics of caregivers relate to their own health and/or the health of the care recipient. Few studies have explored how the social and contextual environment, including the support available to caregivers, may be associated with the ART outcomes of drug using PLHIV. Within the context of Baltimore, high rates of poverty, substance use and incarceration likely affect the ART outcomes of PLHIV not only directly, but also indirectly through their effects on their caregivers. The purpose of this analysis is to identify the support network characteristics of caregivers of PLHIV that are associated with the care recipient having an undetectable viral load. Study findings from a predominately African American urban population, contribute unique information on the social environment of HIV caregiving in a population vulnerable to virologic failure. Such data can inform future health promotion programs to support both the caregivers' and care recipients' health outcomes.

METHODS

Procedure

Data are from the baseline survey of the BEACON (Being Active and Connected) study, conducted from 2008–2012. This study examined social environmental factors associated with health outcomes and well-being among disadvantaged PLHIV and their informal caregivers (32). Care recipients were recruited from both an HIV specialty clinic associated with Johns Hopkins Hospital, as well as through community sampling and street outreach. Inclusion criteria for care recipients were: (a) age of 18 years or older; (b) documented HIV sero-positive status; (c); current or former injection drug use; (d); current use of ART regimen defined as use in the prior 30 days; and (e) willing to invite at least one main supporter to participate in the study.

Main supporters, or caregivers, were eligible to participate if they had provided care recipients with emotional, instrumental, and/or health-related assistance in the prior six months. Caregiver exclusion criterion was providing care to the recipient in a professional (paid) capacity. As described in an earlier publication, up to three caregivers were recruited for each care recipient. If a care recipient had more than three caregivers, priority on who to include was determined based on a ranking of the support the caregivers provided (33). In the case of ties in the ranking of these caregivers priority was given, based on our previous

findings of care recipient preferences and sources of intensive caregiving, to the enrollment of main partners, female kin, male kin and friends (34). For this study, analyses were restricted to recipients' main (or sole) caregiver. All participants completed baseline and follow-up assessments. Serum viral load, CD4 count data, and toxicology tests were collected for all care recipients. The BEACON study received ethical approval from the Johns Hopkins Bloomberg School of Public Health's Institutional Review Board.

Measures

Outcome—The outcome variable was the care recipients' undetectable plasma HIV viral load (Roche Cobas Amplicor) using a cut-off of less than 50 copies per mL (35).

Independent Variables

Caregiver characteristics: Socio-demographic variables included age, sex, race, education, and role relationship to the care-recipient (kin, friend, or main partner/spouse). HIV status of the caregiver was also assessed. Given that all care recipients were HIV positive, the HIV status of the caregiver indicates if the caregiver/care-recipients were sero-concordant or discordant dyads. Depressive symptoms were measured by the Center for Epidemiologic Studies Depression Scale using an established cut point of 16 or more to identify individuals at risk for clinical depression (36). Physical functioning was a summed score of six items including being able to walk one block, engaging in moderate to vigorous exercise, and needing help with personal care. A higher score indicated worse physical functioning (37). Caregiver's current drug use was measured by binary items indicating use of at least one of the following illicit drugs in the past 6 months: stimulants, opiates, tranquilizers, heroin, cocaine, hallucinogens.

Characteristics of the caregiver's support network: Social network data were collected based on the Arizona Social Support Interview Schedule (38), eliciting first names and the first initial of the last name of persons perceived available to provide emotional, instrumental, financial, informational, and socialization (recreational) support. Next, characteristics of each person named were elicited including their sex, age, drug use status, role relation (e.g. spouse/partner, kin, friend), and frequency of contact. Caregivers' network characteristics included the numbers of support network members perceived emotionally, instrumentally, and financially supportive, if the support network members used illicit drugs in the past year, and the number of support network members who were non-kin. Non-kin members could include any of the following: friends, neighbors, godparents, godchildren, someone at work, the friends of relatives, roommate, and narcotic anonymous and alcoholic anonymous program sponsors. Partners were not included as non-kin members. Emotional support was measured as the number of support network members the caregiver could talk to about things that are personal or private. Frequency of contact with support network members was recorded on an ordinal scale that ranged from 1=less than once a year to 6=every day. Responses were averaged across all the support network members, and treated as a continuous variable in regression analysis. Caregivers were also asked how many youth (ages 8–17 years) they currently care for, and if the youth has had any involvement in the criminal justice system (e.g. ever brought to a police station, or ever been in jail, prison, or a residential detention center).

Data Analysis—Care recipients were first matched with a single caregiver who the recipient identified as the most supportive caregiver in his/her network. Data from this care recipient/caregiver dyad were then analyzed. Frequencies and means for the caregiver characteristics were generated for the independent variables, and compared to the outcome of undetectable HIV RNA among the care recipients. Factors marginally statistically significant ($p < .10$) at the bivariate level were included in a multiple logistic regression model. Two covariates were also included in the model. One covariate assessed the caregiver's own current drug use as drug use among network members may be spurious and conflated with the caregiver's own drug using status. The other covariate was the caregiver's physical functioning limitations, a factor found to be significantly related to care recipient's having an undetectable viral load in a previous analysis (18). All variables were simultaneously entered into the regression model and then removed one at a time with a stepwise deletion approach until the final model was reached using a significance level of $p < .05$. Finally, additional analyses tested for statistically significant interactions between variables of interest. All analyses were conducted using SPSS Version 20.0 (39).

RESULTS

Caregiver characteristics

Out of the full sample of care recipients ($N=383$), 258 had a caregiver enrolled in the study. Due to missing biomarker data from recipients, 242 Recipient-Caregiver dyads were retained. Among these dyads, 43.0% of the caregivers were kin, 36.8% were the partner/spouse of the care recipient and 19.0% were friends. The average age of caregivers was 47 years. On average the caregiver had known the care recipient for 19 years ($SD=17$). Caregivers were predominately African American (88.8%), had a minimum of a high school education (77.7%), and were female (59.1%). Forty-two percent of caregivers were HIV sero-positive themselves (42.6%).

Factors associated with an undetectable viral load among care recipients

At the bivariate level, marginally and/or statistically significant factors associated with an undetectable viral load in the care recipient included caregiver's older age, being male and having greater physical functioning impairment. Among caregivers' support network characteristics, marginally and/or significant associations were found between the care recipient's undetectable viral load and the following: more frequent network member contact, greater numbers of support network members who are not kin, having fewer support network members using illicit drugs, and having fewer youth who are involved in the criminal justice system (Table 1).

In adjusted analyses, which retained only significant main effects ($p < .05$) and two covariates, caregiver's physical functioning limitations and current drug use, four independent variables were significantly associated with care recipients' undetectable viral load (Table 2). Results indicated that for each additional child a caregiver cares for who is in the criminal justice system, the care recipient had a 68% decreased odds of having an undetectable viral load (Adjusted Odds Ratio [AOR] = 0.32; 95% Confidence Interval [95% CI] = 0.11, 0.95). Care recipients also had a 50% decreased odds of having an undetectable

viral load if the caregiver was female (AOR = 0.50; 95% CI = 0.27, 0.94), and a 25% reduction in the odds for every active drug user in the caregiver's support network (AOR = 0.75; 95% CI = 0.57, 0.99). A greater number of non-kin in the caregiver's support network, however, increased the odds of the care recipient's having an undetectable viral load (AOR = 1.24; 95% CI = 1.01, 1.50). The Nagelkerke R-square value was .123, indicating 12.3% of the variance in viral load was explained by the independent variables in the final model.

DISCUSSION

This study is among the first to examine the role of caregivers' individual and support network characteristics in achieving an undetectable viral load among HIV care recipients. In adjusted analyses, care recipients' odds of having an undetectable viral load was significantly and negatively associated with their caregiver providing care for youth involved in the criminal justice system, being female, and having more current drug users in their network. These data also showed that greater numbers of non-kin members in the support networks of caregivers was positively associated with achieving an undetectable viral load among care recipients. These findings highlight the importance of support network research and provide insights into potential interventions for achieving undetectable viral loads among drug using PLHIV, especially social support interventions among female caregivers raising high risk youth.

In communities most impacted by HIV/AIDS and high incarceration rates, caring for youth involved in the criminal justice system is not uncommon and is likely highly stressful to caregivers. Pearlin and colleagues identified two sources of stress that impact mental health among caregivers of PLHIV: primary stressors related directly to caring for someone living with HIV and secondary stressors that encompass the effects of caregiving on other social roles (40). They posit that primary stressors could generate secondary stressors. The impact of these stresses on the health outcomes of caregivers may vary by context and background conditions and resources, such as caregiver relationship to the recipient and experiences of HIV-related stigma (40). In the present study, caring for troubled youth, in addition to the HIV sero-positive care recipient, may constitute a potential secondary stressor and is an understudied aspect in the caregiving literature. Caregiving in this context may involve navigating a complex health care system while simultaneously navigating the labyrinth of the judicial system with minimal pertinent resources. It is plausible that caring for youth involved in the criminal justice system impacts care recipients' viral load through several different mechanisms including potential effects on caregivers' mental health, their access to and availability of resources important to their care provision, and/or the quality of the caregiving relationship. Youth involved in the criminal justice system may also be indicative of the degree of disadvantage or drug involvement that exists in the shared network of the caregiver and care recipient.

These findings correspond with results from the Gender, Race and Clinical Experience (GRACE) trial that found lower adherence and virologic response among PLHIV who were female and the primary caregivers of children (41). HIV care and support services do not typically address competing childcare, or any caregiving needs and responsibilities of PLHIV or their caregivers, though they may impede health behaviors and affect poor health

outcomes. Our prior findings showed ART adherence among HIV-positive women was lower if they had an HIV-positive partner. This finding suggests that competing caregiving demands in sero-concordant relationships affect women's own adherence behaviors (42). The present study expands on this evidence to suggest that competing caregiving demands experienced by caregivers may impact their care recipients' HIV outcomes. These findings support the development and testing of family approaches to HIV care and treatment that directly address issues of children and family caregiving responsibilities. Such interventions may be informed by network analyses to identify the multiple roles and kinds of support caregivers have in order to develop and test interventions to address their varied needs that influence their caregiving abilities, e.g. provision of childcare during clinic appointments, training peer supporters to augment existing support networks, and developing innovative strategies to navigate the challenges of drug use, incarceration and poverty.

Results also indicated that the majority of caregivers were female and that having a female caregiver was associated with care recipients' detectable viral load. In our prior research, we found that female compared to male caregivers of drug using PLHIV had smaller support networks, which was associated with greater perceived caregiver role overload and depression (20). Caregiver role overload and depression are both major components of caregiver burden that have been found in other populations to predict the cessation of caregiving (26, 28, 43). Given the gendered nature of caregiving, it is plausible that females are more likely than males to provide care to severely ill PLHIV. In that case, female caregivers' smaller support networks may be a consequence of their social isolation with more intensive caregiving demands and burden. It is also plausible that female caregivers' limited support networks may in turn impede their caregiving ability.

This study also found that having a greater number of non-kin in the caregivers' support networks was positively associated with achieving an undetectable viral load among the HIV-positive care recipients. This finding is consistent with a previous study that found that caregiver contact with friends was significantly associated with the caregiver's reports of greater perceived emotional support and instrumental assistance (44). These results may be explained by lower affiliative HIV stigma or drug use-related stigma among caregivers' supportive friends who are aware of their caregiving role. In a prior study in this population, disclosure of HIV caregiving was found to be associated with caregivers' lower level of depressive symptoms (22). Also, the findings may be due to differing norms regarding social exchange by role relation. There is often lower availability and greater costs associated with receiving social support from friends as compared to family members, and friends are generally expected to provide more immediate and similar forms of reciprocated support (45). As such, caregivers who have more non-kin support may have more resources to develop and maintain relationships of choice. Further research should explore how such findings pertaining to non-kin network members vary with the illness stage of the care recipient and with caregiver burden.

In the present study, a greater level of active drug use in the caregiver's support network, independent of the caregiver's own drug use, was associated with reduced odds of having an undetectable viral load among currently or formerly drug using care recipients. In addition, over a third of the caregivers reported current drug use, and substance use among the support

network members of these caregivers is likely far higher than in non-drug using HIV and caregiving populations (18). Persons actively using drugs often violate norms of reciprocity to their social network members, and in a disadvantaged community often place inordinate demands on the limited resources of their network members (46, 47). Having more drug users in one's support network may impede the emotional and instrumental assistance provided to the recipients' by diverting caregivers' support resources and exacerbating stress and caregiver burden. To support the HIV health outcomes of PLHIV interventions to facilitate entry into addictions treatment should extend to their caregivers and support network members. Ultimately, addressing caregiver burden is important to avoid caregiver burnout and early cessation of care, thereby increasing the likelihood of achieving an undetectable viral load among this vulnerable PLHIV care recipient population (18, 28).

Limitations

The present study is subject to several limitations. First, data were cross-sectional, which prevents the interpretation of causal relationships among the variables of interest. Therefore, for example, we cannot determine from this study if having a female caregiver leads to a greater odds of detectable viral load, or if poor virologic outcomes lead to having a female primary caregiver. Second, the generalizability of the study is limited because all BEACON care recipients were enrolled in HIV primary care and on ART. Therefore, they may not represent most African American PLHIV, or most individuals with a history of injection drug use. Additionally, analyses only included care recipients who had enrolled a main supporter in the study. Therefore, study design and findings are only applicable to PLHIV who report access to informal caregiving, though prior research suggests that the vast majority of former or current drug using PLHIV (and three-fourths of current injection drug using PLHIV in the prior multisite INSPIRE Study) report availability of informal HIV care (17).

Conclusions

Our findings offer novel insight into informal caregiving and provides critical evidence for developing an informal caregiver intervention for the unpaid friends, families and partners of former or current drug using PLHIV. Study findings highlight how PLHIV with a history of injection drug use and their informal caregivers share a unique socio-contextual environment which impact both their informal care and HIV health outcomes. These findings suggest that in this context HIV treatment interventions should engage family and support networks to address the needs of caregivers who care for PLHIV and youth involved in the legal/justice system. Network analysis can inform intervention design to promote informal caregiving relationships and address the social support needs of caregivers, especially among women caring for PLHIV and high risk youths.

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Table 1

Bivariate analysis of caregiver characteristics associated with current or former drug using HIV positive care recipients' undetectable viral load (Beacon Study, N=242)

	N	242	Total %	Care recipients undetectable (n=173), %	Viral load detectable (n=69), %	Unadjusted Odds Ratio (95% CI)	P-value
Caregiver Background Demographics							
Age (mean, SD)	47.1 (11.0)	--	--	48.0 (10.8)	44.8 (11.1)	1.03 (1.00–1.06)	0.041
Physical functioning limitations (mean, SD)	3.8 (3.5)			4.1 (3.6)	3.1 (2.9)	1.09 (1.00, 1.19)	0.049
Sex: Female	143	59.1		54.9	69.6	0.53 (0.29–0.97)	0.038
Race: non-Hispanic black	215	88.8		90.8	84.1	1.86 (0.82–4.25)	0.140
Education: High School	188	77.7		76.3	81.2	0.97 (0.55–1.73)	0.920
Drug use, past 6 months	84	34.7		32.4	40.6	0.70 (0.39–1.25)	0.226
Depressive symptoms	77	31.8		32.4	30.4	1.10 (0.60–2.02)	0.749
Living with HIV	103	42.6		43.9	39.1	1.22 (0.69–2.15)	0.496
Relationship with care-recipient							
Partner	89	36.8		37.0	36.2	1	
Kin	104	43.0		44.5	39.1	0.64 (0.30–1.35)	0.241
Friend	46	19.0		16.8	24.6	1.06 (0.56–2.00)	0.848
Care recipient/caregiver sex							
Male/Female	94	38.8		36.4	44.9	1	
Male/Male	47	19.4		20.2	17.4	1.44 (0.67–3.14)	0.370
Female/Female	49	20.2		18.5	24.6	0.93 (0.45–1.92)	0.837
Female/Male	52	21.5		24.9	13.0	2.35 (1.02–5.43)	0.045
Social Support Network Characteristics (mean, SD)							
Number in the support network	4.93 (2.34)	---		5.06 (2.29)	4.59 (2.45)	1.10 (0.96–1.25)	0.165
Frequency of network contact	1.88 (0.57)	---		2.57 (0.58)	2.73 (0.53)	.60 (.36–1.00)	0.050
Number in network who could provide emotional support	2.23 (1.18)	---		2.32 (1.23)	2.00 (1.03)	1.30 (0.99–1.71)	0.061
Number of non-kin in support network	1.82 (1.74)	---		1.98 (1.81)	1.48 (1.43)	1.21 (1.01–1.46)	0.041
Number of network with current drug use	0.86 (1.13)	---		0.76 (1.10)	1.09 (1.18)	0.79 (0.62–1.00)	0.048
Number of criminal justice involved youth (8–17) being cared for by caregiver	0.07 (0.27)	---		0.04 (0.20)	0.13 (0.38)	0.32 (0.12–0.87)	0.026

Table 2

Final multivariable model of caregiver characteristics associated with current or former drug using HIV positive care recipients' undetectable viral load (Beacon Study, N=242)

	Adjusted Odds Ratio (95% CI) **
Female caregiver (vs. male caregiver)	0.50 (0.27,0.94) *
Number of criminal justice involved youth (8–17) being cared for by caregiver	0.32 (0.11,0.95) *
Number of current drug users in caregiver's support network	0.75 (0.57,0.99) *
Number of non-kin in caregiver's support network.	1.24 (1.01, 1.50) *

*
p<.05

**
Controlling for caregiver current drug use and physical functioning limitations