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## Informal Caregiver Characteristics Associated With Viral Load Suppression among Current or Former Injection Drug Users Living with HIV/AIDS

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### Abstract

**Background**—Few studies have examined the association between having an informal (unpaid) caregiver and viral suppression among persons living with HIV/AIDS (PLHIV) who are on antiretroviral therapy. The current study examined relationships between caregivers' individual and social network characteristics and care recipient viral suppression.

**Methods**—Baseline data were from the BEACON study caregivers and their HIV seropositive former or current drug using care recipients, of whom 89% were African American (N=258 dyads).

**Results**—Using adjusted logistic regression, care recipient's undetectable viral load was positively associated with caregiver's limited physical functioning and negatively associated with caregivers having few family members to turn to for problem solving, a greater number of current drug users in their network, and poorer perceptions of the care recipient's mental health.

**Conclusion**—Results further understandings of interpersonal relationship factors important to PLHIV's health outcomes, and the need for caregiving relationship-focused intervention to promote viral suppression among PLHIV.

### Keywords

HIV/AIDS; viral load and suppression; care recipients; informal caregivers; social networks

## INTRODUCTION

With the advent of antiretroviral therapies (ART), persons living with HIV/AIDS (PLHIV) are living longer, but with growing levels of impairment due to chronic illnesses that often occur sooner among PLHIV<sup>1</sup>. Having a detectable viral load is associated with PLHIV's higher morbidity, physical and cognitive impairments, and mortality<sup>2,3</sup>. The most effective

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way to achieve undetectable viral load and prolonged physical health is sustained ART adherence, which is more difficult to achieve with active drug users<sup>4,5</sup>.

PLHIV have increasing needs for informal (unpaid) care, with most of this care provided by family, main partners, and friends<sup>6,7</sup>. PLHIV without these supportive social network members may have increased risk of detectable viral loads and this risk may increase with growing disability associated with HIV/AIDS.

While much research with caregivers has focused on the impact of care recipients' problem behaviors and negative support on caregivers' burden and well-being, increasing research attention has been given to the impact of informal caregiving relationships on care recipients' physical and mental health outcomes.<sup>8,9</sup> For example, prior studies with urban samples indicate that informal care is predictive of viral suppression and other health outcomes for PLHIV<sup>10,11</sup>. Previous research also indicates that caregiver factors, such as instrumental and emotional support provision, open communication, and affirmative caregiver/recipient interactions improve care recipients' health outcomes<sup>12-16</sup>.

Little research exists that has explored associations between caregivers' supportive network members and care recipient health outcomes. However, one study examined the triangular relationship between health professionals, caregivers, and care recipients in promoting the latter's physical health outcomes<sup>17</sup>. Although this study suggests medical personnel may provide valuable support to caregivers, little is known about the support that caregivers receive from their own social networks and how this support may impact the quality of care given to the recipient<sup>17</sup>.

The purpose of this study was to assess the relationship between caregivers' individual level factors (e.g., sex, age, physical limitations), dyadic characteristics (e.g., caregivers' perceptions of recipients' mental health, satisfaction with relationship), and caregivers' social network factors (e.g., number of drug users in caregiver network and family support) and PLHIV's plasma viral load. Results from this investigation will further an understanding of the relationship between caregiver social resources and care recipient viral load, which could suggest foci for interventions for improving care recipients' viral loads.

## METHODS

### Procedure

Data were from 258 caregiver/care-recipient dyads from the baseline assessment of the BEACON (Being Active and Connected) study, which examined social environmental factors associated with physical and mental health outcomes including ART treatment adherence among disadvantaged persons living with HIV in Baltimore, Maryland. Participants were recruited from clinic and community venues. Selection criteria included being an HIV seropositive adult, former or current injection drug user, currently taking ART, Baltimore City residence, and being willing to invite one's main supportive individual(s) to participate in the study. Caregivers were selected based on criteria of PLHIV care recipient report of s/he having provided the recipient general emotional or instrumental assistance and health-related assistance in the prior six months, and the recipient having

authorized the caregivers' recruitment to the study. Caregiver exclusion criteria included providing care to the recipient in a professional (paid) capacity. The study on which this manuscript is based is fully approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board. All caregivers and care recipients, including those with and without participating caregivers, completed informed consent.

## Measures

**Outcome**—The outcome variable was undetectable plasma viral load as measured by the Roche Cobas Amplicor. Values were dichotomized with undetectable (<50 copies per mL) = 1 versus detectable (≥ 50 copies per mL) = 0<sup>18</sup>. Approximately 6% of the sample (n = 16) were missing data on the outcome measure, making the final sample size n = 242. A sensitivity analysis comparing caregiver characteristics for care recipients with viral load data versus those without indicated no significant differences for caregivers' demographic variables (sex, age, race/ethnicity, income) and significant study variables.

**Independent variables**—Individual level caregiver variables included sex, age, race/ethnicity, education, income, HIV status, and physical functioning limitations, which were measured by 6 summed items with the stem, "How much does your health affect your ability to..." and physical competencies such as, "bend, lift, or squat down."<sup>19</sup> Additional variables included substance use (0 = no substance use in past 6 months, 1 = used drugs such as opiates, heroin, cocaine, stimulants, barbiturates, or hallucinogens in the past six months or binged on alcohol in the past 30 days) and depressive symptoms (Center for Epidemiologic Studies – Depression) cut at 16<sup>20</sup>.

Caregiver/care recipient relationship was characterized as either main partner, kin, or friend. Emotional support was measured with the item, "The care recipient is someone I can count on to listen to me when I need someone to talk to," with responses dichotomized as 0 = Strongly disagree/disagree vs. 1 = Strongly agree/agree. Caregiver perceptions of care recipient mental health was measured by, "Overall, would you say the care recipients' mental health in the past 6 months was..." "Excellent" = 1 to "Poor" = 5.

Network data included family support, which was measured by the item, "In my family, there are only a few family members that we go to when we have a problem." Answer choices were Strongly Disagree/Disagree = 0 vs. Strongly Agree/Agree = 1. Also, the number of support network members who used drugs within the past year was dichotomized as 0 = none vs. 1 = one or more.

**Data Analysis**—Frequencies and means were generated for the dependent and independent variables in SPSS Version 20.0<sup>21</sup>. Unadjusted odds ratios were calculated and those significant at  $p < .05$  at the bivariate level were entered into an adjusted model. Non-significant variables in the adjusted model were omitted, except for sex, age, and relationship type, which were control variables.

## RESULTS

Of the informal caregivers (N = 258), the majority were female (59.3%), African American (89.1%), poor (<\$1,000 per month income) (63.7%) and currently using drugs and/or bingeing on alcohol (53.1%) (Table 1). Approximately one-third had high depressive symptoms (32.7%) and 43.4% were HIV seropositive. Caregivers reported good emotional support from their care recipient (91.1%). The mean score of caregivers' perceptions of recipients' poor mental health status was 3.0 on a scale of 1 to 5. Most respondents reported few family members to turn to with a problem (75.6%), and approximately half had at least one network member who had used drugs in the past year (51.2%).

The majority of care recipients were African American or Black (84.5%), earned less than \$1,000 per month (81.4%), and almost half (48.8%) had less than a high school education (data not shown). Less than half of care recipients were female (42.6%), had a partner as their main supporter (38.4%), had high depressive symptoms (40.5%), and had used substances (42.2%). Mean age was 48.

Bivariate associations indicated that caregivers who were older or had more physical limitations had significantly greater odds of caring for a recipient with an undetectable viral load (Table 1). In contrast, caregivers who were female, had perceptions that their care recipients had poorer mental health status, had few family members to turn to with problems, and had more network members who used drugs in the past year had significantly greater odds of caring for a recipient with a detectable viral load.

The adjusted analysis, which controlled for caregiver sex and age, and caregiver/care recipient relationship type, indicated caregivers with greater physical functioning limitations cared for recipients with significantly greater odds of having an undetectable viral load (Table 1). In contrast, caregiver perception of recipient's poor mental health status was associated with reduced odds of the care recipient having an undetectable viral load. Also, having few family members to go to with a problem and having one or more network members who used drugs in the past year was associated with care recipients' greater odds of having an undetectable viral load. The non-significant Hosmer-Lemeshow chi-square test indicated good model fit.

## DISCUSSION

The purpose of this study was to identify caregiver factors associated with care recipient viral load among a care recipient population who is vulnerable to failed HIV treatment. Caregiver network and interpersonal factors associated with the recipient's detectable viral load included caregivers having few family members from whom to seek help, more network members who were current substance users, and poorer perceptions of recipient mental health status.

In contrast, higher scores on the physical functioning limitations scale were associated with greater odds of recipients having an undetectable viral load. This may indicate the caregiver's greater illness severity and increased likelihood of ART knowledge and treatment experience. It is likely that caregivers with greater physical limitations may have

more experience giving and receiving care, possibly including care exchange with the recipient. It is also possible that caregivers with greater physical health problems are less likely to take on the responsibilities associated with caring for a more impaired care recipient who is more likely to have a detectable viral load. However, more research is needed to fully understand this association.

The findings of having few family members to turn to for problem solving being associated with recipient detectable viral load suggests that these caregivers may have less supportive family relations, and points to the importance of collaborative family problem solving in addressing challenges to network members' ART outcomes. This finding is consistent with previous research with HIV/AIDS and cancer caregivers that suggests that caregivers with more family support may provide more effective care<sup>22,23</sup>. Additional research has indicated that stronger family and peer network ties may enhance caregiver well-being, which in turn can influence quality of care, and care recipients' health outcomes, such as viral load<sup>5,24</sup>. Therefore, our finding suggests that enhancing caregivers' supportive family networks may aid in improving the health of care recipients.

Caregivers having current drug users in their social network was associated with the care recipient having a detectable viral load. While drug use by PLHIV and their support network members has been associated with detectable viral load and other worse health outcomes, this is the first study to find that the caregiver's support network level of drug use is associated with the recipient's worse HIV health outcomes. While it is possible that the care recipient is a drug user in the caregiver's network, the study finding suggests that the caregiver faces additional challenges in relying on the support of active drug using persons, and in ways that impede their effective caregiving. Having drug users in the caregiver's social network could also negatively impact the quality of care that the caregiver can provide to the recipient. These findings suggest the need for further research and intervention to address the environmental context of informal caregiving for this vulnerable population.

Caregiver perceptions of the recipient's poor mental health status was associated with recipients having a detectable viral load. Research has shown that caregivers can accurately perceive poor mental health status in care recipients, as suggested by previous research that indicated moderate agreement between caregivers' reports and care recipients' reports of the latter's mental health status<sup>25</sup>. It is well established that care recipients who are depressed have lower rates of viral suppression<sup>26-28</sup>. Further research should seek to clarify potential mediators of these associations, including interpersonal caregiving relationship factors. Additionally, treatment or prevention of mental illness among caregivers and care recipients may prolong informal caregiving and sustain positive influences on the care recipient's viral suppression<sup>29-30</sup>.

### Limitations

The data were cross sectional, which precludes definitive conclusions regarding causal direction. Additionally, the caregiver data was self-report, which may be subject to social-desirability and recall bias. Because this was a secondary analysis, measures for the survey were not specifically chosen for this study. Also, because many of the measures used in

research with caregivers of PLHIV are adapted from research with different chronic disease populations, few studies exist that establish the psychometric properties of these items<sup>31</sup>. Therefore, follow-up studies should seek to establish the validity of these items.

## Implications

Having greater availability of family problem solving support appears to be an important resource for caregivers helping recipients to achieve an undetectable viral load. Therefore, interventions may be focused on strengthening the family network and helping families cope with challenges by collaboratively defining and addressing problems. Collaborative problem solving research has indicated the importance of problem solving skills to maintaining low viral loads<sup>32</sup>.

The results also suggest that strengthening relationships between caregivers and care recipients can promote undetectable viral load among care recipients, possibly as a result of an increased amount and quality of care. Therefore, researchers and clinicians should promote virologic outcomes with interventions that address barriers in caregiver/care recipient relationships. Reducing potential barriers such as poor mental health status and current substance use could also strengthen the caregiving relationship. However, more caregiver factors should be explored in follow-up studies to better understand these relationships. In particular, future studies should focus on mechanisms to explain these associations by examining potential mediators, such as the quality of instrumental and emotional support, in the associations between caregiver individual and network characteristics with care recipient viral load status.

## Conclusions

Little research has focused on individual and network factors of caregivers that may influence the health of care recipients, especially those with HIV/AIDS. The current study begins to fill a gap in the literature by looking beyond individual factors of PLHIV that influence HIV treatment adherence and corresponding viral load. In the current study, we found evidence that caregiver and dyadic characteristics between caregivers and care recipients, along with caregivers' support network factors and hindrances, are associated with care recipient viral load. These findings help to illuminate the role of the informal caregiving relationship for HIV-positive care recipients' health outcomes and point to the need for caregiver-care recipient dyad focused intervention to promote HIV health outcomes in similar populations.

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## References

1. Fisher M, Cooper V. HIV and ageing: premature ageing or premature conclusions? *Current Opin Infect Dis.* 2012; 25(1):1–3.
2. Wolf MS, Davis TC, Osborn CY, et al. Literacy, self-efficacy, and HIV medication adherence. *Patient Educ Couns.* 2007; 65(2):253–260. [PubMed: 17118617]

3. Mannheimer S, Friedland G, Matts J, Child C, Chesney M. The consistency of adherence to antiretroviral therapy predicts biologic outcomes for human immunodeficiency virus-infected persons in clinical trials. *Clin Infect Dis*. 2002; 34(8):1115–21. [PubMed: 11915001]
4. Wood E, Hogg RS, Lima VD, et al. Highly active antiretroviral therapy and survival in HIV-infected injection drug users. *JAMA-J Am Med Assoc*. 2008:550–554.
5. Tucker JS, Burnam MA, Sherbourne CD, Kung FY, Gifford AL. Substance use and mental health correlates of nonadherence to antiretroviral medications in a sample of patients with human immunodeficiency virus infection. *Am J Med*. 2003:573–580. [PubMed: 12753881]
6. Kimberlin C, Brushwood D, Allen W, Radson E, Wilson D. Cancer patient and caregiver experiences: communication and pain management issues. *J Pain Symptom Manage*. 2004; 28(6): 566–78. [PubMed: 15589081]
7. Knowlton AR, Curry A, Hua W, Wissow L. Depression and social context: primary supporter relationship factors associated with depressive symptoms among a disadvantaged population with HIV/AIDS. *J Community Psychol*. 2009:526–541.
8. Rodakowski J, Skidmore ER, Rogers JC, et al. Role of social support in predicting caregiver burden. *Arch Phys Med Rehabil*. 2012; 93:2229–2236. [PubMed: 22824248]
9. Bass DM, Judge KS, Snow AL, et al. Negative caregiving effects among caregivers of veterans with dementia. *Am J Geriatr Psychiatry*. 2012; 20(3):239–247. [PubMed: 22251867]
10. Knowlton AR, Latkin CA. Network financial support and conflict as predictors of depressive symptoms among a highly disadvantaged population. *J Community Psychol*. 2007; 35(1):13–28.
11. Edwards LV. Perceived Social Support and HIV/AIDS Medication Adherence Among African American Women. *Qual Health Res*. 2006; 16:679–691. [PubMed: 16611972]
12. Beals KP, Wight RG, Aneshensel CS, Murphy DA, Miller-Martinez D. The role of family caregivers in HIV medication adherence. *AIDS Care*. 2006; 18(6):589–596. [PubMed: 16831787]
13. Knowlton AR, Arnsten JH, Gourevitch MN, Eldred L, Wilkinson JD, Rose CD, Buchanan A, Purcell DW. Microsocial environmental influences on highly active antiretroviral therapy outcomes among active injection drug users. *J Acquir Immune Defic Syndr*. 2007; 46(2):S110–S119. [PubMed: 18089980]
14. Knowlton AR, Yang C, Bohnert A, et al. Informal care and reciprocity of support are associated with HAART adherence among men in Baltimore, MD, USA. *AIDS Behav*. 2011; 15:1429–1436. [PubMed: 20632081]
15. Bachner YG, Carmel S. Open communication between caregivers and terminally ill cancer patients: the role of caregivers' characteristics and situational variables. *Health Commun*. 2009; 24(6):524–31. [PubMed: 19735030]
16. Wittenberg-Lyles E, Demiris G, Oliver DP, Burt S. Reciprocal Suffering: Caregiver Concerns During Hospice Care. *J Pain Symp Manage*. 2011; 41(2):383–393.
17. Talley RC, Crews JE. Framing the public health of caregiving. *Am J Public Health*. 2007; 97(2): 224–228. [PubMed: 17194871]
18. Arribas JR, Horban A, Gerstoft J, et al. The MONET trial: darunavir/ritonavir with or without nucleoside analogues, for patients with HIV RNA below 50 copies/ml. *AIDS*. 2010; 24(2):223–230. [PubMed: 20010070]
19. Lawton MP, Brody EM. Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist*. 1969; 9:179–186. [PubMed: 5349366]
20. Radloff LS. CES-D scale: A self-report depression scale for research in the general populations. *Appl Psych Meas*. 1977; 1:385–401.
21. IBM Corporation. IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corporation; 1999.
22. Stetz KM, Brown MA. Physical and psychosocial health in family caregiving: A comparison of AIDS and cancer caregivers. *Public Health Nurs*. 2004; 21:533–540. [PubMed: 15566558]
23. Dyer TP, Stein JA, Rice E, Rotheram-Borus MJ. Predicting depression in mothers with and without HIV: The role of social support and family dynamics. *AIDS Behav*. 2012; 16(8):2198–2208. [PubMed: 22311149]
24. Mosack KE, Petroll A. Patients' perspectives on informal caregiver involvement in HIV health care appointments. *AIDS Patient Care STDS*. 2009; 23(12):1043–1051. [PubMed: 19929228]

25. Mitchell MM, Robinson AC, Wolff JL, Knowlton AR. Perceived mental health status of injection drug users living with HIV/AIDS: Concordance between informal HIV caregivers and care recipient self-reports and associations with caregiving burden and reciprocity. *AIDS Behav.* 2014; 18(1):1103–1113. [PubMed: 24385229]
26. Carrico AW, Bangsberg DR, Weiser SD, et al. Psychiatric correlates of HAART utilization and viral load among HIV-positive impoverished persons. *AIDS.* 2011; 25(8):1113–1118. [PubMed: 21399478]
27. Gonzalez JS, Batchelder AW, Psaros C, Safren SA. Depression and HIV/AIDS treatment nonadherence: A review and meta-analysis. *J Acq Immunity Def Syndr.* 2011; 58(2):181–187.
28. Mehta S, Moore RD, Graham NM. Potential factors affecting adherence with HIV therapy. *AIDS.* 1997; 11(14):1665–1670. [PubMed: 9386800]
29. Kaaya S, Eustache E, Lapidus-Salaiz I, et al. Grand challenges: Improving HIV treatment outcomes by integrating interventions for co-morbid mental illness. *PLoS Med.* 2013; 10(5):e1001447. [PubMed: 23700389]
30. Reich WA, Lounsbury DW, Zaid-Muhammad S, Rapkin BD. Forms of social support and their relationships to mental health in HIV-positive persons. *Psychol Health Med.* 2010; 15(2):135–145. [PubMed: 20391231]
31. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist.* 1990; 30(5):583–594. [PubMed: 2276631]
32. Gross R, Bellamy SL, Chapman J, et al. Managed problem solving for antiretroviral therapy adherence. *JAMA Intern Med.* 2013; 173(4):300–306. [PubMed: 23358784]



**Table 1**

Frequencies and means of informal HIV caregiver characteristics and their unadjusted and adjusted associations with undetectable viral load among former or current drug using persons on antiretroviral therapy (N = 258).

<b>Variables</b>	<b>N (%) or Mean (SD)<sup>a</sup></b>	<b>OR<sup>b</sup></b>	<b>95% CI<sup>c</sup></b>	<b>AOR<sup>b,de</sup></b>	<b>95% CI<sup>c</sup></b>
<i>Individual-level factors</i>					
Sex (female)	153 (59.3)	.53*	.29, .97	.53	.27, 1.05
Age	47.3 (11.1)	1.05*	1.00, 1.06	1.02	1.00, 1.05
Race/Ethnicity (African American/Black)	229 (89.1)	2.14 <sup>§</sup>	.92, 4.98		
Education (less than high school)	100 (38.8)	.97	.55, 1.73		
Income (< \$1,000 per month)	160 (63.7)	.89	.49, 1.60		
Physical Functioning Limitations	3.7 (3.4)	1.09*	1.00, 1.19	1.12*	1.02, 1.24
Substance use (current)	137 (53.1)	.68	.38, 1.19		
Depressive symptoms (CES-D: high)	84 (32.7)	1.01	.98, 1.03		
HIV seropositive	112 (43.4)	1.22	.69, 2.15		
<i>Caregiver/recipient relationship</i>					
Main caregiver relationship					
Partner	99 (38.4)	1.36	.64, 2.87	1.32	.57, 3.06
Kin	110 (42.6)	1.52	.73, 3.16	1.57	.69, 3.62
Friend	46 (17.8)	1.00		1.00	
Emotional support (yes)	235 (91.1)	1.85	.75, 4.54		
Perceptions of recipient's poor mental health	3.01 (1.14)	.66 <sup>**</sup>	.50, .86	.66 <sup>**</sup>	.50, .89

<sup>§</sup>  $p < .10$ ,

\*  $p < .05$ ,

\*\*  $p < .01$ ,

\*\*\*  $p < .001$

<sup>a</sup> SD = Standard Deviation

<sup>b</sup> OR = Unadjusted Odds Ratio

<sup>c</sup> CI = Confidence Interval

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<sup>e</sup> AOR = Adjusted Odds Ratio

<sup>e</sup> Adjusted model fit: Hosmer and Lemeshow test  $\chi^2 = 11.15$ ,  $df = 8$ ,  $p = .19$ .

Note: Due to 16 respondents missing viral load data, the logistic regression equations have  $n = 242$ .