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Informal HIV caregiver proxy reports of care recipients' treatment adherence: Relationship factors associated with concordance with recipients' viral suppression

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Abstract

Objective—To explore the role of informal caregivers in adherence, we compared adherence reports by caregivers to those of care recipients. We identified individual-level and relationship factors associated with agreement between caregivers' reports of recipients' adherence and assessed viral suppression.

Methods—Participants were care recipients, who were on ART and had ever injected drugs, and their caregivers ($N=258$ dyads).

Results—Nearly three-fourths of caregivers' reports of recipients' ART adherence agreed with recipients' viral suppression status. Agreement was associated with recipient age and expressing affection or gratitude to the caregiver, caregiver's having been close to someone who died of HIV/AIDS, and caregiver's fear of caregiving-related HIV (re)infection, while it was negatively associated with recipient's limited physical functioning.

Conclusions—Our findings support the utility of caregiver proxy reports of care recipients' ART adherence and suggest ways to identify and promote HIV caregiver attention to and support of this vulnerable population's ART adherence.

Keywords

Informal HIV caregiving; Black/African American; Injection drug/substance abuse; antiretroviral therapy adherence; Measurement concordance/agreement

INTRODUCTION

Informal caregiving relationships, in which emotional support or instrumental assistance is provided without pay to a partner, family member, or friend, have robust effects on the

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health and well-being of persons with serious chronic conditions, including persons living with HIV/AIDS (PLHIVs).^{1,2} Informal caregivers may be especially important to substance using and African American PLHIVs, whose poor adherence to ART contributes to their persistent disparities in HIV morbidity and mortality.^{3–6} Prior research suggests that informal HIV care and caregiving relationship factors are associated with improved ART adherence and virologic outcomes among HIV seropositive care recipients, many of whom are African American and current substance users.^{7–10}

Low income African Americans, compared to other economic and racial/ethnic groups, have higher rates of HIV/AIDS and are more likely to report providing informal HIV care.^{11–12} In such a context, HIV caregivers may themselves be living with HIV, or may be close to someone with HIV or AIDS. These experiences may affect their understanding of the importance of ART adherence to PLHIVs' health and, therefore, their attentiveness to their care recipient's ART adherence.

Caregivers may be more accurate in their reports of the recipient's adherence because they may be less subject to social desirability bias in their proxy reports as compared to recipient self-reports.¹³ For example, a prior study of main partners of HIV seropositive men who have sex with men (MSM) found evidence that main partners' reports of ART adherence were a potentially superior indicator of viral suppression as compared to patients' self-reports of adherence.¹³

Caregivers of PLHIVs may affect the latter's health in part by facilitating treatment adherence.^{14–16} Caregivers' care provision and attention to recipients' medication adherence may be influenced by interpersonal communication and emotional support exchange, which are indicators of caregiving relationship quality.^{1,2} Reciprocity of social support is normative in interpersonal relationships, and relationships characterized by mutual support exchange is predictive of greater health impact of social support.^{17–19} In contrast, violating reciprocity norms may strain caregiving relationships, or diminish care provision or effective functioning.¹⁷ In a prior study with drug-using, predominantly African American men on ART, having informal HIV care was positively associated with ART adherence, but only to the extent that they reciprocated support to their caregiver.¹⁷

Caregiving role relation may also influence caregivers' attentiveness to care recipients' medication adherence. For example, caregiving norms may differ for kin ties as compared to friendships.²⁰ Caregiver-recipient co-residence may also be important as it facilitates caregivers' direct observation of recipients' medication adherence.

ART adherence sufficient to achieve viral suppression significantly reduces the risk of HIV transmission.²¹ Caregivers may be motivated to tend to recipients' ART adherence out of concern for potential HIV (re)infection from their caregiving-related exposure to care recipients' bodily fluids.

Study objectives

The present study is the first to examine caregiver reported ART adherence in a disadvantaged drug using population. We compared the association between caregiver proxy

reports of recipients' ART adherence and recipients' viral load, and between recipient self-reported adherence and associated viral load. Secondly, we identified caregiver and recipient individual-level and relationship factors associated with caregivers' accuracy of reports of recipients' ART adherence. Investigating the accuracy of caregivers' reports of care recipients' treatment adherence, and factors associated with caregivers' accurate adherence reports, will help identify adherence attentive caregivers. It is particularly important to identify engaged caregivers and inform adherence intervention for populations vulnerable to failed treatment and health disparities. The study extends the literature by identifying relationship factors associated with the precision of caregivers' proxy reports.

METHODS

Data and procedures

Data were from the BEACON study, which examined social environmental factors associated with health outcomes and well-being among disadvantaged PLHIVs and their informal caregivers.^{22–24} Care recipients were recruited from an academic adult HIV clinic and community venues. Selection criteria included being an HIV seropositive adult, currently or formerly injecting drugs, currently taking ART, living in Baltimore, and being willing to invite a main supportive tie(s) to participate in the study. The study was approved by the Johns Hopkins Bloomberg School of Public Health's Institutional Review Board and all participants provided fully informed consent. Participants were compensated for their time and effort.

Caregivers were selected based on criteria of the care recipients reporting that the caregiver provided the recipient with emotional, instrumental, or health-related assistance (e.g., assistance with medications or attending medical visits) in the prior six months, and recipient authorization of the caregiver's recruitment to the study. Caregiver exclusion criteria included being paid to provide care to the recipient. Up to three caregivers were recruited per recipient, with priority given according to ranking based on range of support provided; in cases of ties in rankings, priority was given to selection in the order of main partners, female kin, male kin, and friends, which is based on our previous findings of care recipient preferences and sources of intensive caregiving.²⁴ For this study, analyses were restricted to recipients' main (or sole) caregiver. Care recipients and caregivers were interviewed separately in face-to-face interviews in a community-based research facility. Audio-computer-assisted self-interview (ACASI) was used for data collection on sensitive topics, including ART adherence and substance use.

Measures

Using an item developed for the BEACON study, caregivers reported their recipient's ART adherence by indicating how adequately they perceived the recipient "takes care of him/herself in terms of taking medications as prescribed, that is, how the doctor says to take them?" (1=very well versus 0=less than very well). Based on prior research and ease of interpretation, recipients' self-reported seven-day ART adherence was dichotomized using a cutoff of 100 percent.²⁵ Plasma viral load (Roche Cobas Amplicor) was dichotomized as 1=undetectable (<50 copies per mL) versus 0=detectable;²⁵ viral load status was considered

an indicator of recipient's true adherence to ART. Concordance was defined as agreement between caregiver report of recipient's high ART adherence and recipient's having an undetectable viral load,¹³ and agreement between caregiver report of adhering less than very well and recipient's detectable viral load, compared to lack of agreement between caregiver reported ART adherence and recipient viral load status.

Independent variables included self-reported caregiver and recipient demographics, current substance use (any illicit drug except marijuana and any hazardous drinking, including binge drinking at least once per week or daily drinking), depressive symptoms, and physical functioning limitations.^{27, 28} Additional self-reported variables included recipient's length of time on ART; caregiver's HIV seropositive status; and caregiver's reports of having had been close to someone who died of AIDS, which was developed for the study.

Caregiver-recipient relationship variables included role relation (kin versus partner, friend or other) and currently living together.²⁸ Caregiver reported relationship quality variables included recipient's reciprocity of caring, assessed as caregiver report that their care recipient in the past year "expressed affection and appreciation to you" (0=never, or 1=some or a lot),²⁹ caregiver-recipient communication, "I can state my feelings about our relationship without the care recipient getting defensive,"²⁸ and caregiver's perceived emotional support from the recipient, "[S/he] is someone I can count on to listen to me when I need someone to talk to."²⁸ Fear of caregiving-related HIV infection was an item developed for the BEACON study, "How much are you afraid of getting infected or re-infected with HIV by caring for a person with HIV or AIDS?" with responses recoded as 0=never versus 1= a little to extremely afraid, based on the distribution of the data.

Analyses

The level of concordance between caregiver proxy-report of recipient's medication adherence and recipient's viral suppression status was examined, including agreement between caregiver report of high adherence and undetectable viral load, and agreement between caregiver report of low adherence and detected viral load. To compare the relative predictive strength of caregiver proxy-report versus recipient self-report of medication adherence, we regressed recipient viral suppression on caregiver proxy-report and on recipient self-report separately in bivariate analyses and together in adjusted analyses.

We then assessed correlates of the caregiver proxy-reported high adherence concordance outcome variable (i.e., agreement of caregiver proxy-reports of recipient high adherence and recipient viral suppression). We examined unadjusted associations between concordance and caregiver and recipient individual-level and relationship factors. Chi-square tests with categorical variables and t-tests with continuous variables were performed using SPSS Version 20.0.³⁰ Variables significant at the $p < .15$ level in unadjusted analysis were entered into a multiple logistic regression model. Only variables that retained at least marginal significance ($p < 0.10$) were included in the final model.

RESULTS

Description of the sample

Of the 383 PLHIVs on ART enrolled in the study, the vast majority (78%) nominated at least one person who provided them assistance, and 67% had at least one caregiver enrolled in the study (total caregivers $N=382$). The analytic sample comprised 258 (main) caregiver-recipient dyads. The majority of care recipients were middle-aged, low income, African American, and male, and reported current substance use (Table I). Caregivers and recipients had similar demographic characteristics except that most caregivers were female (Table I). Approximately one-third of caregivers reported that they feared HIV infection or reinfection (35.7%) and more than half had someone close to them die from AIDS (58.9%) (Table I).

Caregiver proxy-report compared to recipient self-report of adherence, in predicting viral suppression

Most ($N=144$; 58.5%) of caregivers' high adherence reports agreed with recipients' viral suppression status, and in 11.2% ($N=27$) of dyads there was agreement between caregiver reports of recipient's low adherence and recipients' detectable viral load (data not shown). Both caregiver proxy-report and recipient self-report of high adherence were predictive of viral suppression. The unadjusted odds ratio (OR) associated with caregiver reports (3.12, 95% CI=1.55, 6.28; kappa = .24, $p < .001$) was slightly higher than the OR associated with recipient report (2.66, 95% CI=1.32, 5.35; kappa = .20, $p = .001$) (Table II). When both of these variables were used in the same model to predict viral suppression, the adjusted odds ratio (AOR) associated with caregiver report was 2.92 (95% CI=1.53, 5.58), and the AOR associated with recipient report was 2.61 (95% CI=1.26, 5.38) (Table II). Thus, the results indicated a higher odds ratio of caregiver proxy-versus self-reported adherence, though the difference was not statistically significant.

Correlates of concordance between caregiver report and viral suppression status

In unadjusted analysis, factors found to be associated with increased odds of concordance were recipient's age, caregiver having experienced someone close die of AIDS, caregiver-recipient kin relation (coded as kin versus partners or friends), caregiver's report that recipient expressed affection and appreciation to him/her, and caregiver fearing HIV (re)infection from caregiving related activities (Table III). Recipient's physical limitations were associated with reduced odds of concordance. In the final multiple logistic regression model, factors associated with increased odds of concordance included recipient age, caregiver having been close to someone who died of AIDS, recipient expressing affection or gratitude to caregiver, and caregiver fear of caregiving-related HIV (re)infection. In contrast, recipients with greater physical limitations had reduced odds of concordance. Caregiver's kin relation was marginally significant.

DISCUSSION

The findings provide further evidence of the caregiver role in ART adherence among a population vulnerable to non-adherence and failed ART, and the potential for intervening with caregivers to promote HIV health outcomes. Our findings indicated that caregivers'

proxy-reports of their recipient's ART adherence were highly concordant with recipient's viral suppression status, and to a degree comparable to recipient's self-reported adherence. It is plausible that accuracy of caregiver proxy reports of the recipient's adherence can be an indicator of attentiveness of the caregiver, the close relationship between caregiver and care recipient, and the caregiver's medication adherence support or assistance to the care recipient. Our results were consistent with findings from a prior study of partners' proxy reported ART adherence of MSM.¹³

Also, we found evidence that caregivers' accurate reports of recipients' ART adherence and corresponding viral load were associated with care recipient's reciprocity of caring (affection or gratitude), older age, and greater physical functioning; caregivers' prior experience of someone close dying of HIV/AIDS; and caregivers' interest in self-protection from caregiving-related HIV (re)infection. Thus, findings of correlates of concordance may represent factors predisposing or motivating adherence assistance and other forms of effective care. Our finding that care recipients who show affection for their caregivers are more likely concordant in the reports of ART adherence and viral load complements previous evidence of associations between care recipient reciprocity of support to their caregivers and the care recipient's lower psychological distress and among men, ART adherence.^{17,31} The results suggest caregivers' expectations of recipients' reciprocity and its effects in promoting the effective functioning of the caregiving relationship. Disadvantaged substance using persons are not only more likely to have HIV and other chronic conditions and care needs, but tend to have more conflictive and less reciprocal relationships.^{32,33} Care recipients' reciprocity may signal to caregivers their mutual investment in the relationship.^{1,34}

We also found that caregiver fears of (re)infection were associated with concordance of adherence reports. It is possible that this fear motivates the caregiver to be more aware of the recipient's use of ART and promotes an attitude of self-preservation. Caregiver fears of HIV (re)infection from the recipient may be especially great among dyads with sexual contact or sharing drugs, and may be heightened for those caregiving in contexts of low resources for ensuring hygienic conditions and avoidance of contact with bodily fluids.

We also found that caregivers who knew someone who had died from AIDS were more likely to be concordant with care recipients in reports of medication adherence and viral load. Caregivers' prior loss of a close relationship to AIDS may be indicative of prior experience with HIV caregiving and understanding of the importance of ART adherence to HIV health outcomes. Results indicated poorer concordance among younger care recipients and those with more physical functioning limitations. The latter finding may be explained by the recipient's greater care needs and challenges obtaining needed care, or, alternatively, may be explained by impaired functioning being confounded with poor medical adherence and immune system dysfunction. This highlights potential risks of caregiving dysfunction in recipients' late-stage illness when their care needs are greatest and when caregivers' proxy reports may be most valuable to healthcare providers for guiding patients' treatment and outcomes.³⁵

Implications

Our findings have implications for potential targets and strategies of interpersonal approaches to ART adherence intervention. Results suggest that persons involved in care recipients' HIV medication adherence and health outcomes can be identified by recipient nomination of persons providing behavioral assistance. The findings suggest that ART adherence interventions ought to emphasize the mutual benefit of adherence to main supportive relationships because adherence can reduce the potential risks of (re)infection. Also, reiterating the potential risks of (re)infection for caregivers can educate caregivers and motivate them to accurately monitor adherence. Interventions could focus on facilitating informal caregiving relevant to ART adherence by promoting PLHIVs' interpersonal reciprocity, such as expressing affection or gratitude to their main supportive ties. Our findings suggest that to promote concordance in adherence reports, interventions could promote empathy for caregivers who had lost loved ones to AIDS. Intervention is especially merited for PLHIV who are younger or are physically impaired.

Limitations

There are several potential limitations of the study that merit consideration. The generalizability of our findings are limited by the selection of PLHIV on ART and mostly (three-fourths) recruited from an academic HIV clinic. Because the data were cross-sectional, we cannot ascertain the direction of associations between independent and dependent variables. Substance use may not have been fully captured by illicit drug use and binge drinking because prescription drug misuse, which was not assessed in the study, may also explain variance in the outcome measure. Also, measurement may also present limitations of the study, such as our use of different measures of caregiver as compared to recipient reported adherence and exclusive use of caregiver reports of relationship measures. However, given the dearth of research on the role of caregivers and other relationship factors in treatment adherence, the study findings are an important contribution to the literature.

Conclusions

The study results indicate that caregiver proxy reports of care recipients' HIV medication adherence may be valid indicators of recipients' adherence. This may be especially critical because caregivers can be proxies reporting to medical providers for care recipients who may be unable to adequately speak for themselves.³⁵ The findings also enhance an understanding of the role of interpersonal relationships in the health and well-being of a vulnerable population, and inform interpersonal approaches to promoting their medical adherence and health outcomes.

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Table I

Sample description: Former or current injection drug using HIV care recipients' and their informal caregivers' individual and relationship characteristics (BEACON study; Baltimore, MD; N=258 dyads).

Characteristic	Care recipient^{&}	Caregiver^{\$}
Individual-level factors	N(%) or Mean(SD) ^a	N(%) or Mean(SD)
Sex: male	148 (57.4)	105 (40.7)
Race/ethnicity: Black/African American	218 (84.5)	229 (89.1)
Education: < high school	126 (48.9)	100 (38.7)
Income: <\$999 monthly	210 (81.4)	160 (62.6)
Drug use or alcohol abuse, current	152 (58.9)	137 (53.1)
Age	47.6 (6.3)	47.3 (11.1)
Depressive symptoms, high	103 (39.9)	84 (32.7)
HIV seropositive	258 (100.0)	112 (43.4)
Physical functioning limitations (range 0–10)	4.6 (3.1)	3.7 (3.4)
Time on ART (years)	10.8 (6.9)	---
Viral load, undetectable	173 (71.5)	---
Caregiver-recipient relationship factors		
Caregiver is kin (vs. partner or friend)		110 (42.6)
Satisfaction with relationship (range 1–10)		8.5 (2.0)
Co-residence		114 (44.2)
Recipient expressed affection and appreciation to caregiver		191 (74.0)
Caregiver-recipient good communication		203 (78.7)
Recipient is a source of caregiver's emotional support		235 (91.1)
Caregiver fears caregiving-related HIV (re)infection		92 (35.7)
Caregiver experienced someone close die of AIDS		152 (58.9)

^{\$} Caregiver self-reports

[&] Care recipient self-reports or relationship reports

^a SD = Standard Deviation

Table II

Associations between care recipient undetectable viral load and reported recipient adherence (BEACON Study, Baltimore, MD, N=258).

Adherence Reports from:	Undetectable Viral Load	
	<u>Odds Ratio (95% CI)</u>	<u>Adjusted Odds Ratio (95% CI)</u>
Caregiver	3.12 *** (1.55, 6.28)	2.92 ** (1.53, 5.58)
Care Recipient	2.66 *** (1.32, 5.35)	2.61 *** (1.26, 5.38)

95% CI = 95% Confidence Interval;

**
 $p < .01$;

 $p < .001$.

Table III

Caregiver, recipient, and relationship factors associated with concordance between caregiver report of recipient's medication adherence and recipient's viral load suppression status (unadjusted odds ratios from simple logistic regression, adjusted odds ratios from multiple logistic regression; BEACON study, Baltimore, MD; N=258).

Variables	Unadjusted odds ratios	95% CI ^a	Adjusted odds ratios	95% CI ^a
<i>Care recipient factors</i>				
Age	1.05*	(1.00, 1.10)	1.06*	(1.01, 1.11)
Current substance use	0.75	(0.42, 1.31)		
Depressive symptoms, high	0.83	(0.47, 1.46)		
Physical functioning limitation	0.89*	(0.81, 0.98)	0.86**	(0.78, 0.95)
<i>Caregiver factors</i>				
Experienced someone close die of AIDS	2.18**	(1.24, 3.83)	2.20*	(1.18, 4.08)
<i>Caregiving relationship factors</i>				
Caregiver is kin (vs. partner, friend or other)	1.80*	(1.00, 3.22)	1.69 [§]	(0.91, 3.16)
Caregiver-recipient co-residence	1.14	(0.65, 2.02)		
Recipient expressed affection and appreciation to caregiver	2.07*	(1.13, 3.78)	1.97*	(1.02, 3.82)
Caregiver fears caregiving-related HIV (re)infection	2.00*	(1.08, 3.71)	2.32*	(1.19, 4.54)

[§] $p < .10$,

* $p < .05$,

** $p < .01$

^a CI = 95% confidence interval