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Latent Growth Curve Analyses of Emotional Support for Informal Caregivers of Vulnerable Persons with HIV/AIDS

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Abstract

Persons living with HIV/AIDS (PLHIV) have growing rates of morbidity and need for informal care, especially among drug using PLHIV. Informal caregivers, or persons providing unpaid emotional or instrumental support, have protective effects on the health and well-being of PLHIV or other serious chronic conditions. Research suggests that social support, including care recipients' reciprocity of emotional support, is important to sustained caregiving. This study examined HIV caregivers' perceived emotional support over time from their current or former injection drug using care recipients. Methods: Data were from baseline, six-, and 12-months follow-up of the BEACON study. Results: Latent growth curve analysis showed a decline in reciprocated emotional support reports over time, particularly among caregivers themselves HIV seropositive or currently substance using. Researchers should develop interventions to strengthen the caregiving relationship by promoting reciprocity of emotional support, with implications for sustaining caregiving to vulnerable PLHIV and improving their health outcomes. Interventions should especially target dyads in which caregivers are also HIV positive and using substances.

Keywords

Informal caregivers; emotional support; reciprocity; substance use; HIV/AIDS

Introduction

Informal caregivers, defined as persons providing unpaid emotional or instrumental support to someone with a serious chronic condition, have significant effects on the physical and mental health of care recipients (Robles & Kiecolt-Glaser, 2003). Specifically, caregivers may be directly involved with their care recipients' adherence, biologic outcomes, and overall quality of life (Uchino, 2004). Informal caregivers may be especially critical to health outcomes in low income chronically ill communities with high numbers of people living with HIV/AIDS (PLHIV) (Knowlton, 2003).

Recently, increases in chronic disease burden have established the importance of understanding caregiver health outcomes. Studies suggest informal caregivers are at risk of

physical and mental health problems (Garlo, O'Leary, Van Ness, & Fried, 2010). Therefore, the role of informal caregiving is highly stressful with potential negative mental health consequences and strains on social relationships (Pirraglia et al., 2005; Prachakul & Grant, 2003; Turner, Catania, & Gagnon, 1994). Depressive symptoms of the recipient, caregiver, or both, may impede prosocial interactions, including emotional support provision or reciprocity.

Although PLHIVs who are former or current drug users may be able to access informal care in their support networks, their caregivers appear to often have limited social support. Research findings with this population suggest that reduced social support may affect caregiving-related strains and early cessation of care (Mitchell & Knowlton, 2012). Additionally, the support from care recipients, which is important for quality relationships, may not be matched to the type most needed for addressing their stress or environmental demands (Cutrona, 1990).

Reciprocity of emotional support to the caregiver can affect the mental and physical health of recipients and caregivers alike. Recipients' reciprocity of emotional support may affect their own health through its effects on the quality of the caregiving relationship and, therefore, relationship continuity and caregiver's willingness to sustain caregiving. Care continuity is particularly important in a drug-using population that has high needs for care, considering the role that caregivers play in recipients' medication adherence and mental health.

The present study addresses a gap in the literature (Prachakul & Grant, 2003) by examining caregivers' longitudinal perceptions of care recipients' reciprocity of emotional support, and correlated caregiver- and recipient-level factors such as caregiver and care recipient age, sex, depressive symptoms, substance use, physical functioning limitations, care recipient viral load, and caregiver HIV status. Findings will inform interventions to promote informal HIV caregiving in a disadvantaged population, with potential implications for continuity of care and health outcomes of both informal caregivers and care recipients.

Methods

Procedure

The BEACON study, which included 258 care recipient/caregiver dyads, was a longitudinal observational study (baseline, six, and twelve month assessments) that examined the development of interpersonal and social-contextual factors that may affect disadvantaged PLHIVs' adherence to ART. Participants were recruited from clinic and community venues. Selection criteria included being an HIV seropositive adult, former or current injection drug use, taking ART, Baltimore City residence, and being willing to invite one's main supportive tie or caregiver to participate in the study. Up to three informal (unpaid) caregivers were recruited, with priority given to main partners (Knowlton, Yang, Bonhert, et al., 2011; Pearlin, Mullan, Semple, & Skaff, 1990). The BEACON study was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Measures

Outcome—The outcome variable was a measure of caregivers' perceptions that they could count on their care recipients to listen and provide emotional support. The item was, “[care recipient] is someone I can count on to listen to me when I need someone to talk to,” with responses measured on a 4-point Likert scale from strongly disagree to strongly agree.

Predictors—Predictors included caregiver and care recipient sex, age, depression, current substance use, physical functioning limitations, care recipient viral load, and caregiver self-reported HIV serostatus. Current substance use was defined as use of heroin, cocaine, hallucinogens, stimulants, barbiturates, or opioids in the past six months; and hazardous drinking. Depressive symptoms were measured with a dichotomized Center for Epidemiologic Studies Depression Scale (CES-D) score (1 = 16+ and 0 = less than 16) (Radloff, 1977). Physical limitations assessed caregiver and care recipients at each time point with five items such as, “How much does your health affect your ability to bend, lift, or squat down?” (Lawton & Brody, 1969). Plasma viral load (Roche Cobas Amplicor) was dichotomized as 1=undetectable (<50 copies per mL) versus 0=detectable (50+ copies per mL) (Arribas, Horban, Gerstoft, et al., 2010).

Data Analyses—Frequencies and means were run on the demographic variables in SPSS v. 22 (2013) and the physical limitations factors were fit in Mplus (Muthén & Muthén, 2009). An unconditional latent growth curve model (LGC) (Curran, 2000) was estimated to confirm a linear longitudinal relationship of the outcome, while a second latent growth model was fit with the intercept and slope factors regressed on caregiver HIV serostatus, care recipient viral load, and caregiver and care recipient depression, current substance use, age, sex, and physical limitations.

Results

Of the 258 care recipients, the majority were African American or Black (84.5%) and earned less than \$1,000 per month (81.4%), while less than half of were female (42.6%). Mean age was 48. Caregivers were primarily African American or Black (88.4%) and female (59.3%), with a mean age of 47. Less than half had HIV/AIDS (43.4%). Compared to HIV-positive caregivers, HIV-negative caregivers were significantly more likely to be female and older, and earn \$1,000 or more per month (Table 1). Among all of the factors, the five physical limitations indicator variables for care recipients and caregivers at each of the three time points had satisfactory loadings ranging from .81 to .94 (not shown).

The unconditional latent growth curve, which fit the data well (Comparative Fit Index [CFI] = .99; Root Mean Square Error of Approximations [RMSEA] = .06) (Hu & Bentler, 1999), indicated a decrease in perceived availability of emotional support from the care recipient (slope = $-.53$, $p = .001$) (Figure 1). Subsequently, the conditional latent growth curve model fit the data well (CFI = .97; RMSEA = .04) (Hu & Bentler, 1999) and indicated that caregivers with HIV had significantly steeper negative slopes for emotional support availability compared to caregivers without HIV/AIDS (Standardized Coefficient = $-.48$, $p < .05$) (Figure 2). Caregivers who indicated substance use had significantly steeper negative slopes for emotional support availability compared to caregivers who did not use substances

in the previous 6 months (Standardized Coefficient = $-.53, p < .05$). Care recipients who were depressed at baseline had caregivers who perceived significantly less emotional support availability (Standardized Coefficient = $-.21, p < .05$).

Discussion

The findings indicated that caregivers perceived a significant decrease in emotional support from care recipients over time. This is a concern given research indicating low social support among caregivers, and the potential impact of low support on caregiver overload and cessation risk. The finding may reflect care recipients' health challenges increasingly interfering with their ability to reciprocate support, or increasing caregiving-related stress which may affect caregivers' support needs or expectations from the recipient.

Results also indicated steeper decreases in reciprocated emotional support among HIV seropositive or current substance using caregivers. It is possible that for these, their own support needs may be increasing over time, which may increase their expectations of emotional support from their care recipients. Caregivers' substance use may also restrict emotional support from other network members, raising their expectations of support from care recipients.

Our results indicated that caregivers of depressed compared to non-depressed care recipients reported lower perceived emotional support from care recipients. Depression treatment for PLHIVs likely could improve their social functioning. However, further research is needed to better understand the relationship between care recipient depression and caregiver perceptions of less emotional support.

Limitations

While conclusions regarding cause and effect relationships are strengthened by using a longitudinal design, it is unknown whether unmeasured personal or relationship factors may explain the study findings. Although the outcome measure has good face validity, there are no studies to our knowledge that have established the validity properties for this measure. A limited number of variables considered theoretically important were measured, while additional variables could add to the understanding of the relationships between the predictors and the outcome.

Conclusions

Results indicated that overall levels of emotional support availability from the care recipient decreased over time, and that care recipient depression, and caregiver HIV seropositive status and substance use, were associated with this decrease. Given the highly stressful and socially constrictive nature of the caregiver role, decreases in perceived support from the care recipient may adversely affect caregiving relationship quality and jeopardize continuity of caregiving. Further research attention should be given to caregiver needs and caregiving relationship dynamics, especially among vulnerable populations with high morbidity and mortality rates and care needs. Dyadic intervention and depression treatment for PLHIVs and addiction treatment of caregivers is warranted given the adverse effects behavioral health problems have on the caregiving relationship.

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Figure 1. Means of agreement with perceived access to emotional support questionnaire item based on raw scores at three points in time (baseline, 6 months, and 12 months) (N = 258).

Figure 2.

Conditional latent growth curve model showing standardized path coefficients leading from baseline predictors to the intercept and slope factors of emotional support and physical limitations factors leading to the outcome variables at baseline, 6 months, and 12 months (N=256).

^aFixed loading.

^bTime interval from initial assessment by 6 months

Squares represent measured variables. Ovals represent latent factors. Indicators for physical limitations factors not shown.

* $p < .05$. Bolded lines significant at $p < .05$.

CG = Caregiver and CR = Care Recipient

Note: Controlling for baseline age and sex for caregiver and care recipient.

Model Fit Indices: Comparative Fit Index [CFI] = .97 and Root Mean Squared Error of Approximation [RMSEA] = .04.

Table 1

Comparisons in demographic characteristics between HIV seropositive and HIV seronegative caregivers (N = 258).

Demographic Characteristic	HIV-negative Caregivers N(%) (n=146)	HIV-positive Caregivers N(%) (n=112)
Sex **		
Male	49(46.7)	56(53.3)
Female	97(63.4)	56(36.6)
Race/Ethnicity		
Other	13(46.4)	15(53.6)
African American	133(58.1)	96(41.9)
Income **		
Less than \$1,000	78(48.8)	82(51.3)
\$1,000 or More	64(68.1)	30(31.9)
	Mean (SD)	Mean (SD)
Age *	48.8(12.8)	45.3(8.03)

* $p < .05$;

** $p < .01$

SD = Standard Deviation