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Chronic Pain Predicting Reciprocity of Support among Vulnerable, Predominantly African-American Persons Living with HIV/AIDS

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Abstract

Objective—Among persons living with HIV/AIDS (PLHIV), approximately two-thirds report moderate to severe pain. Chronic pain can negatively affect PLHIVs' health behaviors and outcomes by interfering with their reciprocity (mutual exchange) of support in their caregiving relationships, which has been found to be associated with PLHIVs' antiretroviral (ART) adherence and viral suppression.

Subjects—Data were longitudinal (baseline, 6- and 12-month follow-up) from 383 PLHIV who were formerly or currently using drugs.

Results—Utilizing a longitudinal lagged fixed effects structural equation model, we found that never having pain in the past 6 months was predictive of increased reciprocity of support. Sub-analyses by care relationship type revealed never having pain was a significant predictor of greater reciprocity for sexual partner caregiving dyads, but not for kin or friend caregiving dyads.

Conclusions—Our study emphasizes the importance of pain management in quality caregiving relationships characterized by reciprocity, which has consistently been found to be associated with stronger, more supportive caregiving relationships and better quality of life. Our findings suggest the importance of pain management intervention for improving reciprocity between vulnerable PLHIVs and their primary caregivers, especially between PLHIVs and caregivers who are current or former sexual partners.

Keywords

HIV/AIDS; African-American; chronic pain; reciprocity of social support; informal caregiving

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Ethical Compliance:

Mary Mitchell has no conflict of interest. Sarina Isenberg has no conflict of interest. Allysha Maragh-Bass has no conflict of interest. Amy Knowlton has no conflict of interest.

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 was obtained from all individual participants included in the study.

INTRODUCTION

Among persons living with HIV (PLHIV), chronic pain is highly pervasive (39–55%).^(1–4) This high prevalence of chronic pain among PLHIV has been attributed to advanced disease, side effects of antiretroviral therapy (ART) and high levels of associated drug use disorders,⁽³⁾ and has a major impact on quality of life.⁽⁵⁾

Beyond individual-level impact, chronic pain can strain relationships between PLHIV and their primary informal caregivers, defined as unpaid persons providing instrumental or emotional support. Among disadvantaged drug-using PLHIV vulnerable to HIV health disparities, informal caregiving has been found to be important for care recipients' health services use and viral load.^(6,7) Caregiving relationships may be especially important to health outcomes of substance-using and African-American PLHIV, and caregiving relationship strains may contribute to their low adherence to ART and persistent disparities in HIV morbidity and mortality.^(8–10)

Reciprocity of support, or the extent to which the care recipient returns the provision of support to the caregiver, is considered a major indication of relationship quality and reciprocity of support between care recipient and caregiver has been associated with long-term physical and mental health outcomes.^(11,12) Care recipients' reciprocity of support may affect their own health through its effects on the quality of their main caregiving relationship. Injection drug users with an informal caregiver to whom they provided greater levels of support were more likely to be adherent to ART medications, virally suppressed, and have better mental health.^(13–16)

The objective of the current study was to assess the influence of chronic pain on reciprocity of support. We hypothesized that never having chronic pain would predict greater reciprocity of support, while conversely, having chronic pain, as indicated by reporting having pain often or always, compared to the group who never had pain, would be predictive of reduced reciprocity. Post-hoc sub-group analyses also explored the relationship between pain and reciprocity among different types of caregiver relationships (i.e., partner, kin, and friend/other). Study findings could further illuminate care recipient factors, such as chronic pain, that influence quality of caregiving relationships. These findings will inform the importance of programs to address chronic pain management in a population with HIV health disparities, and social pathways through which such programs may help to promote their health and well-being.

METHOD

Procedure

Data were from the baseline, 6- and 12-month follow-up surveys of the BEACON (Being Active and Connected) study.⁽¹⁵⁾ This project was an observational study which examined social environmental factors associated with health outcomes and well-being among disadvantaged PLHIV and their informal caregivers. PLHIV were recruited from clinic and community venues. Selection criteria included being an adult who is HIV seropositive on antiretroviral treatment, living in Baltimore City, being either a current or former injection

drug user, and being willing to invite one's main supportive tie(s) to participate in the study. The study was fully approved by the Johns Hopkins Institutional Review Board.

Measures

Outcome—Reciprocity of support, which was assessed at all three time points, was measured by six items representing instrumental, emotional, financial/material support, and socialization/companionship including, “How much have you helped your caregiver around the house in the past year,” and “How much have you given or lent money or something valuable to your caregiver in the past year,” with answer choices 0 = None, 1 = Some, and 2 = A lot.⁽¹²⁾ These measures comprised the observed indicator variables for a latent factor, which evidenced face validity because the items appear to be reasonable examples of reciprocity of support and construct validity because the factor has been associated in expected ways with other variables, such as mental health status and antiretroviral therapy adherence, both measures related to relationship quality.^(15, 16)

Predictors—Chronic pain was measured at baseline and 6-months with one item, “In the past 6 months, how often have you been bothered by pain?” with response choices 0 = Never, 1 = Sometimes, 2 = Often, 3 = Always.⁽¹⁷⁾ Based on substantive meaning, this item was trichotomized into 0 = Never, 1 = Sometimes, and 2 = Often or Always.

Data Analysis

First, three exploratory factor analyses (EFAs) were conducted at all three time points (baseline, 6-months, and 12-months), to assess the fit of three latent reciprocity of support factors. Specifically, we wanted to determine how well the indicator variables at each time point loaded on the single latent factors. Subsequently, these factors, along with the pain variables at baseline and 6-months, were entered into a structural equation model that used fixed-effects and lagged predictors.

A fixed effects analysis allows for controlling all time-invariant predictors, both known and unknown, and both measured and unmeasured.^(18,19) To perform a fixed effects analysis in an SEM framework, a second order factor, which we named “alpha,” was created to control for time invariant confounders and was allowed to correlate with all of the predictor variables at baseline and 6-months, as well as with the baseline reciprocity of support factor.^(18,19) The fixed effects technique is used in studies that have panel data, or information from the same group of respondents over time.

Also, panel data allows for lagged effects, in which we can test the influence of baseline predictors on 6-month outcomes, and the influence of 6-month predictors on 12-month outcomes. Combining the lagged effects and fixed effects approaches, therefore, supports stronger conclusions for causality, based on the temporal nature of the data and controlling for time-invariant potential confounders.⁽¹⁸⁾

All of the paths that were tested in the model for the current study are shown in Figure 1. The 6-month and 12-month reciprocity factors load on the fixed effects factor, “alpha,” which was allowed to correlate with reciprocity at baseline, pain measures at baseline, and

pain measures at 6 months. In addition, the pain measures and baseline reciprocity were allowed to correlate with each other.

Additionally, post-hoc analyses were run to explore whether relationship type had an effect on the strength of association between pain and reciprocity. To this end, we split the sample into three sub-groups including partners ($n = 121$), kin ($n = 173$), and friends/others ($n = 89$) and re-ran the analyses separately for each.

RESULTS

The sample of care recipients were primarily Black or African-American (85.9%) and earned less than \$1,000 per month (79.9%) (Table 1). More than half of the sample was male (61.4%) and had used substances in the previous six months (63.3%).

Most caregivers were Black/African American (89.1%), earned less than \$1,000 per month (62.6%), were female (59.3%), and were current substance users (53.1%). Nearly half of caregivers (43.4%) were HIV positive or had AIDS and nearly half (44.2%) resided with the care recipient. Also, caregivers were family members (42.6%), main partners (38.4%), or friends (17.8%). The vast majority of caregivers provided numerous forms of support for their care recipients including preparing food (93.0%), helping with managing money or paying bills (91.8%), and providing transportation (86.5%) or running errands (88.3%).

Few participants reported never reciprocating support to their main caregivers (Table 2). The six reciprocity of support items loaded on the single reciprocity of support factor for baseline (loadings ranged from .62 to .84), 6-months (loadings ranged from .61 to .88), and 12-months (loadings ranged from .59 to .80) (Table 2). The fairly high loadings are indicative of good reliability for the reciprocity factors.

Never having chronic pain at baseline, compared to the reference group, often or always having pain, predicted significantly more reciprocity of support at 6 months ($b = .31$, $\beta = .16$, $p < .05$), and never having pain at 6-months predicted significantly more reciprocity of support at 12-months ($b = .31$, $\beta = .20$, $p < .05$), while controlling for time invariant covariates (Figure 2). The final model achieved good model fit (Comparative Fit Index (CFI) = .96; Root Mean Square Error of Approximation (RMSEA) < .06, 90% Confidence Interval (CI) = .05, .07).⁽²⁰⁾ The chronic pain variables and the alpha factor explained 56% of the variance in the 6-month reciprocity of support factor and 68% of the variance in the 12-month reciprocity of support factor. The standardized regression coefficients of .16 and .20, which are equal to Cohen's d , represent small effect sizes.^(21, 22)

The post-hoc sub-group analyses by relationship type (partner, kin, friend/other) revealed significant effects between pain and reciprocity for partners only. These effects were stronger than those for the overall model. Baseline pain predicted 6-month reciprocity ($b = .83$, $\beta = .46$, $p < .05$) and 6-month pain predicted 12-month reciprocity ($b = .83$, $\beta = .55$, $p < .05$).

DISCUSSION

The purpose of the present study was to assess the impact of chronic pain on a vulnerable PLHIV population's reciprocity of support (instrumental, material or socialization) to their main caregivers. To our knowledge, ours is the first study to consider the role of chronic pain on HIV care recipient reciprocity of support, a key indication of relationship quality and health promoting impact. In addition, reciprocity not only impacts relationship quality, but has been associated with PLHIVs' adherence, viral suppression, and mental health.^(13–16)

The structural equation model results indicated that never having pain had a significant positive effect on reciprocity of support, while controlling for all time invariant potential confounders (fixed effects) and establishing a temporal order for the variables (lagged effects). Our analyses suggest that reducing chronic pain through more effective pain management could lead to stronger reciprocity of support in caregiving relationships, which likely would strengthen the bond between care recipient and caregiver, increasing the likelihood of caregiver relationship health impact over time.

It is possible that our finding of never having pain predicting better reciprocity, or conversely, having pain often or always predicting low reciprocity of support, is explained by the stress and tension that chronic pain can place on individuals as well as their relationships. This result may also be due to the increased amount and types of caregiving the PLHIV with chronic pain may need from a caregiver or that those PLHIV with greater impairment or pain may have different role relations to their caregivers (e.g., family or main partners vs. friends) and that these roles have lower expectations of immediate reciprocity of support. Because PLHIV with chronic pain have greater disability and associated reduced reciprocity of support, this may adversely affect the quality of the caregiving relationship and their caregivers may be at especially high risk of caregiving burnout and care cessation.

The post-hoc analyses revealed strong, significant effects for pain predicting reciprocity of support at each timepoint, but only for caregivers who were current or former sexual partners. It is likely that reciprocity is expected following provision of help to the care recipient either immediately or promised in the future. This lack of immediate reciprocity may be a reason for discord in the relationship and may ultimately disrupt the functioning of the relationship, leading to cessation of care.

Limitations

Although the model used a fixed-effects lagged longitudinal design with responses on the independent variables predicting the responses on the dependent variables at the next time point, it may not necessarily establish causality. Differing timeframes of the survey items (e.g., the timeframe for chronic pain was 6-months, while the timeframe for reciprocity of support was 12-months) may mean that responses were in reference to concurrent experiences rather than sequential events. Also, the construct of reciprocity of support is multi-faceted and the current study only captured some of the types of behaviors that may comprise aspects of reciprocity of support important to health.

Implications

The results suggest the importance of improved pain management programs not only for affecting PLHIVs' health directly, but also affecting their health and well-being through its potential impact on the quality of their main supportive relationships. Increasing HIV caregivers' knowledge and skills to support care recipients' pain management-related behaviors may help to promote vulnerable PLHIVs' health outcomes and well-being, and improve their relationship quality. According to social learning theory, a dyad-level intervention on existing supportive relationships key to health-related support could have major influence on the introduction and reinforcement of vulnerable population's pain management-related behaviors.⁽²³⁾

Pain management is also important for PLHIV at end-of-life or palliative care. A strong relationship between patients and their main caregivers is an essential component of the care triad in palliative care for persons with serious chronic conditions at any stage of illness. Indeed, for a strong care triad including the medical provider, caregiver, and patient, strong relationships are needed between each member of the triad. Palliative care focuses on assessing and improving physical and mental health, social well-being, ensuring shared understanding and medical decision making among patients, caregivers/family and medical providers, and coordinating patients' care, all of which is aimed at increasing the quality of life of patients and their caregivers/family.⁽²⁴⁾ Our study suggests that improved management of chronic pain may help strengthen the bond between HIV caregivers and care recipients with chronic pain, who disproportionately have a history of drug use disorder. Management of chronic pain may help caregiver dyads who are sexual partners in particular given the strong relationship between pain and reciprocity in these dyads. Therefore, pain management intervention is especially warranted for these dyads in which the care recipient experiences chronic pain.

Conclusions

Our study emphasizes the importance of pain management in having caregiving relationships characterized by reciprocity of support, which has been associated with stronger and more supportive caregiving relationships and better quality of life.⁽¹⁵⁾ Increasing reciprocity of support through interventions is especially important given that caregiving strains can increase the number and magnitude of problems (e.g., reduced financial resources and decreased physical and mental health) for caregivers, which in turn affects the care recipients due to their dependence on their caregivers.^(14,25) Future research and interventions should promote prolonged reciprocity of support in caregiving relationships, especially among disadvantaged PLHIV.

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Figure 1.

Figure showing all of the proposed pathways in the lagged, fixed-effects structural equation model.

Ovals denote latent factors; straight, one-headed lines represent regression pathways; and curved double-headed arrow lines represent correlations.

Figure 2.

Care recipient reports of chronic pain significantly predicts care recipient-reported reciprocity in a lagged, fixed effects structural equation model (BEACON study; $N = 383$). Bold lines indicate significant paths at $p < .05$. Dotted lines indicate non-significant paths.

Table 1

Demographic characteristics of persons living with HIV (PLHIV) with a history of injection drug use (BEACON study; N = 383)

Variable	N (%) or Mean (SD) ^a
Sex (male)	235 (61.4)
Race/ethnicity (Black/African-American)	329 (85.9)
Education (High School/GED or less)	321 (83.8)
Income (< 1,000 per month)	306 (79.9)
Depression (16+ on CES-D)	155 (40.5)
Substance use	243 (63.3)
Viral load (Undetectable)	251 (70.7)
Age	48 (6)

^aSD = Standard Deviation

Table 2

Frequencies and factor loadings for care recipient-reported items comprising the reciprocity latent factors (BEACON study; N = 383)

Variable Description	Frequencies for Baseline Reciprocity Items N (%)			Factor Loadings		
	None	Some	A lot	Baseline	6- mo.	12-mo.
Reciprocity						
Helped CG around house	68(17.8)	143(39.8)	148(41.2)	.72	.70	.69
Spent time with CG	4(1.1)	82(24.0)	273(76.0)	.80	.74	.80
Given or lent money to CG	60(16.7)	186(51.8)	113(31.5)	.78	.72	.74
Given things to CG	18(5.0)	149(41.5)	192(53.5)	.84	.88	.79
Shown affection or appreciation	4 (1.1)	49 (13.6)	306 (85.2)	.67	.62	.59
Participate in family activities	57 (15.9)	129 (35.9)	173 (48.2)	.62	.61	.67

CG = Caregiver