Published in final edited form as:

AIDS Behav. 2011 October ; 15(7): 1429–1436. doi:10.1007/s10461-010-9749-1.

Informal Care and Reciprocity of Support are Associated with HAART Adherence among Men in Baltimore, MD, USA

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Abstract

Research suggests gender differences in interpersonal relationship factors important to health. This study examined relationship factors associated with HAART adherence among men. The sample (n=154) comprised 95% African Americans and 48% current illicit drug users; 83% reported HAART adherence. Results revealed adherence was associated with comfort level taking HAART in the presence of close friends, and the interaction between informal care (having someone to care for oneself when sick in bed) and reciprocity of support. Among those with informal care, higher reciprocity of support to caregivers was associated with greater adherence. Promoting men's reciprocity of support to their caregivers and enhancing peer norms of medication taking are important strategies for improving men's adherence. The findings complement previous findings on relationship factors adversely associated with women's adherence. Results suggest the merit of interventions targeting men and their informal caregivers, particularly main partners, and gender-specific, contextually tailored strategies to promote HAART adherence.

Keywords

HIV/AIDS; adherence; highly active antiretroviral therapy; male gender; informal caregiving; reciprocity of social support

INTRODUCTION

Social support is one of the most consistent predictors of adherence to highly active antiretroviral therapy (HAART) [1]. Recent study findings suggest the major role of supportive relationships in explaining HAART adherence, including among drug users at high risk for failed HAART and among low resource communities [2]. Identifying aspects of existing supportive relationships associated with HAART adherence will inform potentially effective, low cost, and sustainable approaches to adherence intervention [3].

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Prior presentation: This data has not yet been publicly presented.

Conflicts of interest: None.

Inconsistencies and gender differences found in prior U.S. studies regarding relationship factors associated with adherence suggest the need for gender-specific research. This study examined relationship factors associated with HAART adherence among community sampled, primarily African American, men in a U.S. HIV epicenter.

Informal caregiving

The vast majority of care to the chronically ill is provided informally by partners, family and friends [4]. Informal caregivers, often defined as individuals voluntarily providing assistance during illness, play a critical role in the social support and physical and emotional well-being of persons with HIV/AIDS [5,6]. Indeed, assistance obtaining or taking medications may be forms of instrumental support provided by informal caregivers. In a study of U.S. injection drug users on HAART, having informal care was predictive of sustained viral suppression over 12 months [7]. African Americans compared to other U.S. racial groups, have high levels of chronic illnesses and provide a disproportionately high level and more intensive forms of informal caregiving, including for those with HIV/AIDS [8,9].

Main partners

Main partners, i.e., spouses or boy/girlfriends, are often important sources of informal care and social support to the chronically ill [10]. Main partner support and caregiving may be especially important to the health of individuals vulnerable to family alienation and failed HAART. Having a main partner has been associated with better HIV outcomes in some studies, including higher HIV survival rates among a Swiss sample [11]. Yet other studies, such as studies of community sampled primarily African American women, and a nationally representative sample of individuals in U.S. HIV medical care, have found that having a main partner was associated with worse HAART adherence [12,13]. These findings suggest the importance of examining functions and qualities of interpersonal relationships, as well as structural aspects of social support (e.g., having a main partner) that may be important to men's HAART adherence.

Relationship quality: Reciprocity of support

Relationships characterized by mutual exchange, or reciprocity, of support are associated with positive appraisals of support, and with better mental and physical health outcomes [14]. In one study, receipt of social support enhanced psychological well-being when it was offered in a mutually supportive relationship [14]. It is plausible that reciprocity is indicative of relationship quality that affects supportive functioning relevant to health [15]. Reciprocity may also promote supportive relationships' ameliorative effects on psychological distress, which may impact physical health directly or indirectly, for example through impeding medical adherence [14,15]. Conversely, findings from British longitudinal studies indicate that lack of reciprocity in main relationships was predictive of higher relative risk of an array of mental and physical chronic conditions, even after adjusting for prior health status [14-16]. According to the theory of reciprocity, violating norms of reciprocity, or only receiving support in a relationship, elicits feelings of dependence, indebtedness, or inferiority, which leads to stress reactions that adversely affect health [14]. Indeed, individuals who report low reciprocity of support in their main relationships have been found to have greater levels of biologic markers of stress response [15].

Reciprocity may be especially important to the health of disadvantaged HIV seropositive individuals. Persons who are poor, depressed, using illicit drugs, or mentally ill, are more likely to be HIV seropositive and in need of support, but tend to have more conflictive, less consistent sources of support, and to be less likely to reciprocate support [17,18]. Active drug use has been associated with exploitative behavior; violating norms of reciprocity while using drugs may strain or jeopardize supportive relationships [19]. Adverse effects of

drug use on supportive relationships may help explain drug users' lower adherence to HAART and higher HIV mortality rates [20-22]. Moreover, hyper-masculine gender roles in African American, drug using popular culture and gender role conflicts [23], may impede HIV seropositive men's reciprocity of support to their primarily female informal caregivers, and the health benefits of such support [24]. The present study examined the potential interactive effect of informal care and reciprocity of support on men's HAART adherence.

Negative support

While considerable research attention has focused on the health promoting effects of social support, increasing evidence indicates that negative support exchanges tend to have stronger and more enduring effects on health [25]. Receipt of social support that is ambivalent or inadequate relative to need or expectation can be stressful, and detract from the health benefits of support [18,26]. Moreover, as negative support and lack of reciprocity of support may be overlapping constructs, examining effects of both factors has been recommended [14].

Privacy

Privacy concerns have been associated with worse HAART adherence; a study of a nationally representative sample of HIV clinic patients found that males were significantly more likely than females to report privacy concerns as reasons for not taking or stopping HAART use[27]. In a sample of drug-using, primarily African American, individuals, feeling comfortable taking HAART in the presence of others was associated with better HAART adherence and greater likelihood of maintaining viral suppression [7,28]. Social discomfort in taking HAART may be indicative of perceived HIV stigma [29], which may vary by role relation. In a heterogeneous sample of HIV seropositive African Americans, higher perceived support from friends, but not from family, was associated with lower perceptions of HIV stigma [30]. The present study separately examined associations between HAART adherence and comfort level taking HAART in the presence of close friends and of close family members.

The present study tested the hypotheses that in a sample of primarily low income African American men, (1) specific function as compared to structural aspects of social ties, as defined by having informal care versus having a main partner or a larger support network, will be more strongly associated with HAART adherence, and (2) reciprocity of support to main supportive ties will be positively associated with adherence.

METHODS

Sample selection

Data were from the ARK (Action through Resources and Knowledge) study (2002-05), a descriptive study of the role of social environmental factors in HIV health outcomes. ARK study eligibility included HIV seropositive status, over age 18 and being a Baltimore, Maryland, U.S. resident. Participants were recruited by street outreach and advertisement at local health and social service agencies, e.g., homeless shelters, drug treatment clinics, HIV medical clinics, and needle exchange programs.

Baltimore has the second highest AIDS case rate of U.S. metropolitan areas [31]. Among those with HIV/AIDS, 89% are African American and 62% are male, as compared to 49% and 74%, respectively, nationally [32]. HIV exposure is primarily from heterosexual activity (47%) and injection drug use (32%) [32].

Surveys were administered face-to-face by trained interviewers using computer-assisted personal interviewing (CAPI). Participants were financially compensated \$25 for their time. Approval of the study was obtained from the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Measures

The outcome measure was 7-day overall mean adherence to at least 90% of doses [33]. In a prior study of current and former drug using methadone maintenance patients, 7 day recall of HAART adherence was found to be highly associated with medication event monitoring system (MEMS) assessed adherence and with viral load [33]. Currently taking HIV medications was defined by self-reports of having a current prescription for any of a regularly updated list of antiretroviral medications, and taking the medication for at least one day during the prior 30 days. Adherence to each antiretroviral medication was assessed by reported doses per day and pills per dose for each antiretroviral regimen prescribed, and report of number of pills missed during the past 7 days. Adherence rate was calculated by dividing the total doses of prescribed medications taken during the past 7 days by the total doses of prescribed medications during the past 7 days.

Independent variables included attitudes toward HAART, which have been found to be associated with adherence [34]. Attitudes were assessed by a 6-item, 4-point response scale, including items such as “Taking HIV medicines makes me think more about AIDS than I want to,” “I think it’s bad news when the doctors suggest you start taking HIV medicines,” and “I don’t like the way my medication makes my body feel.” Responses were coded by degree of agreement or disagreement; the Cronbach’s alpha was 0.77. Current illicit drug use was defined as use of any of a list of substances in the past three months, including heroin and cocaine but excluding marijuana, in various forms and modes of administration.

Depressive symptoms were assessed by the Centers for Epidemiological Studies Depression (CES-D) Scale, a 20-item, 4-point response scale, using a cut-off score of 20 (Cronbach’s alpha=0.91) [35]. Although a cut-off score of 16 has been used to indicate high risk of a clinically meaningful level of depressive symptoms in general population samples, some investigators recommend using a cut-off score of 20 to reduce the number of false positive classifications of depression, particularly within drug using and other subpopulations known to have high rates of depression [36].

Social comfort level taking HAART was asked as, “How comfortable are you taking your HIV medications in front of close friends? And “...in front of close family members?” Responses were recorded on a 4-point scale, and recoded as 1=uncomfortable (very or somewhat uncomfortable) versus 2=comfortable (very or somewhat comfortable). Informal care perception was assessed by response on a 4-point scale of the degree to which the participant agreed with the statement, “I have someone who would help care for me if I was sick in bed for several weeks.” The variable was recoded as disagree (=1 or 2) versus agree (=3 or 4).

Perceived negative support was measured by a five-item scale based on prior studies [25,37], including such items as, “How often have you felt that someone close to you... is not paying enough attention to you? wishes s/he were less obligated to help you? resents or acts hostile about helping you?”[37] Responses were coded on a 4-point scale, from rarely to most or all of the time. The Cronbach’s alpha was .78. Responses were recoded as high (above the median) versus low.

Support network size was defined by numbers of kin and friends in one’s support network. A support network inventory elicited names of perceived support network members, that is,

those whom the participant could rely on for various forms of support in the prior 6 months. The network inventory included items that elicited names of sources of emotional support (Who could you talk to about something personal or private?), health advice, help with getting medical care, and assistance with medication taking [38,39]. Prior studies suggest predictive and concurrent validity of the network survey instrument in the study population (Cronbach's $\alpha=0.85$) [40]. An additional question asked who the most helpful person is in helping the participant deal with HIV, other than a service provider (termed main supporters). Subsequent to name elicitation, participants were asked various characteristics, such as role relation, of individuals named. Variables representing the size of the friend and kin support networks were created by separately summing the number of friends in the support network, and the number of kin (not including main partners). It has been proposed that because such support network inventories emphasize interactional, or behavioral, dimensions of support, and tend to elicit names of relatively few individuals supportive in multiple ways, the network so elicited represents main supportive ties [41].

Reciprocity of support was assessed by a 7-item scale of supporter reports of types of assistance participants provided to their main supporters in the prior year. The types of support reciprocated included instrumental (helped around the house), financial or material (given or lent money, given gifts), socialization (spent time with him/her), and emotional support (expressed affection or appreciation) [37], as well as other potentially contextually relevant items (i.e., participated in his/her family activities, and helped care for his/her children, friends or family). Responses were recorded on a 3-point scale of none, some, or a lot. The alpha was 0.72. Scores ranged 0-14, and were recoded as high (above the median) versus low.

Data analysis

Chi-square tests for categorical variables and t-tests for continuous variables were used to calculate unadjusted associations between the dependent and independent variables. Variables chosen for inclusion in the simultaneous entry logistic regression model were those significant at $p<0.10$ in the unadjusted analysis. Results of the final model are reported in adjusted odds ratios and 95% confidence intervals. To test for possible interactive effects, the interaction term and constituent variables were entered into the model.

RESULTS

Sample description

The sample comprised current or former drug users, of whom the vast majority (79%) had a history of incarceration (see Table I). Over a third (34%) reported daily or binge alcohol use. The mean age was 44 years (range 20-60 years), and mean number of HIV primary care visits in the prior 6 months was 4.40 (SD 4.35). Seventeen percent of participants reported non-adherence to HAART (taking <90% of doses in the prior 7 days).

The vast majority (82%) perceived availability of informal care, and 66% reported feeling comfortable taking HAART in the presence of close friends, as did 80% in the presence of close family members (Table I). The mean score of reciprocity of support was 9.23 (SD 2.90), out of a possible range of 0-14. The mean score of negative support was 6.55 (SD 2.59), of a possible range of 0-20.

Unadjusted and adjusted analyses

In unadjusted analysis, HAART adherence was associated with current drug use, favorable attitudes towards HAART, feeling comfortable taking HAART in the presence of close friends, perceived informal care, reciprocity of support, and negative support (Table I).

Results also revealed that perceived availability of informal care was highly associated with nominating one's main partner as the person "most helpful to you in living with HIV" ($p < .01$).

Adjusted analysis revealed that, independent of current drug use and favorable attitudes toward HAART, adherence was associated with feeling comfortable taking HAART in the presence of close friends, and with an interaction between having informal care and reciprocity of support to main supportive ties (Table II). Specifically, among those who reported having someone to care for them if they were sick in bed, HAART adherence was associated with providing a greater level of support to main supporters. Among those who reported no informal care, there was no difference between reciprocity of support and adherence. Because negative support was not significant and the model was better fit without it, the variable was omitted from the final model.

DISCUSSION

Consistent with the hypotheses and the prior literature on the role of social ties in health outcomes [42], the study results revealed that a specific function of ties was more important to HAART adherence than was mere availability of ties. Specifically, adherence was associated with having social ties that provide informal care, but was not associated with having a main partner or a larger number of friends or kin in one's support network. The findings also suggested that the men's reciprocity of support was critical to the effective functioning of their most supportive ties. Among participants with informal care, those who reported providing greater support to their main supportive ties were more likely to be adherent to HAART.

Results revealed the role of peers in HAART adherence, and identified important targets and strategies of gender-specific intervention to promote HAART adherence in the study population. Indeed, men's having an informal caregiver was highly associated with their having a main partner, a finding which complements findings of main partner factors adversely associated with HAART adherence among women in the community [43]. Feeling comfortable taking HAART in the presence of close friends was also found to be associated with adherence.

Informal caregiving

Further research is needed to better understand informal HIV caregiving relationships in this population and appropriate approaches to enhancing their sustained effectiveness over time. Caregiving is often highly stressful and constrains caregivers' material resources, physical and mental health, and their own social support [44-46]. Caregiving is especially stressful if the caregiver is also impoverished, chronically ill, or if the care recipient has a stigmatizing condition or exhibits disruptive behavior, such as substance abuse [47,48]. Caregiving-related strains, in turn, have been found to predict cessation of informal caregiving [49].

In disadvantaged communities most impacted by HIV/AIDS, informal caregiving often constrains already limited economic and material resources and health status [1,24]. Moreover, HIV is often clustered in family and social networks, compounding community caregiving needs, including care to children neglected or orphaned by parental drug use or HIV/AIDS [50,51]. As caregiving is typically a female gender role, particular attention is needed to minimize the socioeconomic and health impact of HIV caregiving on women and girls in disadvantaged communities [51-56].

Reciprocity

The study findings are consistent with literature indicating that mutually supportive social ties as compared to less reciprocal ties confer greater health benefits [14]. It is plausible that study findings can be explained by participants' lower levels of drug use or negative support, or positive psychological effects of support received from mutual exchange ties [57-60]. While there was no evidence in the present study to suggest such interactive effects on adherence, the limited sample size may have precluded such findings. Further analysis is warranted to explore these potential pathways to adherence in the sample.

Though depressive symptoms were not found to be directly associated with adherence, they may affect adherence through their association with caregiver relationship factors. In a prior study of a similar sample, HIV seropositives' depressive symptoms were associated with their financial dependence on their main supporter and with their main supporter's own depressive symptoms; better communication with their main supporter was protective of depression [61].

The finding of health benefits of reciprocal ties may also be indicative of the positive effects that reciprocity has on caregivers, or expectations of support exchange in this caregiver population. In a US study of impaired older women and their caregiving daughters, women's reciprocity of support was associated with their caregivers' lower perceived stress and caregiving burden [62]. Qualitative study findings on a low resource Ugandan community suggest that achievement of successful HAART was attributed to HIV seropositives' HAART adherence as reciprocation to their main supporters in order to avoid impairment that necessitates supporters' more demanding informal caregiving [2].

Further research is needed to examine the types of support exchange expected, and ways to promote norms of HAART adherence and adherence assistance, particularly among peers [3,63], for whom caregiving may be non-normative. Norms, or expectations, of reciprocity in relationships have been found to differ by role relation of ties, ethnicity, and social context [64,65]. For example, greater, or more immediate, reciprocity is often expected of peers as compared to main partners or kin ties [65]. Non-reciprocity of support has been theorized to contribute to stresses of negotiating caregiver and care recipient roles [48]. In a prior study of a similar population, main supporters who were same generation peers (not including main partners) reported less reciprocated support from their HIV seropositive support recipients as compared to main supporters who were main partners or older or younger generation kin [61]. Furthermore, having non-partner peers as main supporters was associated with HIV seropositives' higher depressive symptoms [61].

Gender and HAART adherence

The present study findings complement findings from a prior study of HAART adherence among women in the study community, and suggest that gender differences in support exchange in this community affect their HAART adherence. The prior study found evidence to suggest that women's non-adherence was associated with their greater caregiving obligations and unreciprocated support from their (HIV seropositive) main partners [12]. For women, HAART adherence was significantly higher among those who did not have a main partner as compared to those with an HIV seropositive main partner [12]. Results from that study also suggested women's unmet support expectations from their main partners: among the majority of women who had a main partner, while most preferred their partner be their main HIV-related supporter, only about a third reported their partner was their main supporter. Furthermore, only about half of the women who had a main partner perceived the partner as a source of emotional support [12], the form of support most often found in the literature to be associated with better health outcomes [12].

Results from the present and the prior study of women are consistent with prior findings of gender differences in psychosocial correlates of HAART adherence. In an Italian study, among men, adherence to HAART was associated with greater relationship orientation, whereas among women, adherence to HAART was associated with less relationship focus [66]. It is possible that stereotypical gender roles in low income African American communities most affected by HIV/AIDS [23] interfere with men's reciprocity of social support in their main relationships, to the detriment of their effective relationship functioning and HAART adherence.

Limitations

The cross-sectional study design precludes determination of the causal direction of statistical associations. Threats to the validity of the findings include self-report and sampling biases, as well as limited sample size and statistical power to detect differences. It should also be noted that the study lacked reports from informal caregivers, which may diverge in important ways from participant reports. Future studies using objective measures of adherence are warranted to verify study findings. However, the findings are consistent with prior findings on the role of informal caregiving and social comfort taking HAART in predicting viral suppression among injection drug using, primarily African American, individuals on HAART [7].

Implications to intervention

The findings suggest intervention targets and strategies to improve HAART adherence among urban, primarily African American, men who are highly impacted by HIV/AIDS and vulnerable to failed HAART. Results suggest the merit of interventions targeting men and their main supportive ties to facilitate informal caregiving; improve their reciprocity of support to their caregivers, including their main partners; and promote peer norms of medication adherence. Further research is needed to identify informal HIV caregivers' resource needs in this disadvantaged population for sustained caregiving over time. Promoting mutual support in men's main supportive relationships and enhancing caregivers' sustained HIV caregiving, may not only enhance men's successful HAART but may also have implications to the well-being of their caregivers and their communities.

Acknowledgments

The study was supported by National Institute on Drug Abuse grants R01 DA019413 and R01 DA13142.

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Table I

Characteristics of men taking HAART in the ARK study, and unadjusted associations with HAART adherence (Baltimore, MD, U.S.; 2002-05; n=154).

	Full sample (n=154) N (%)	Adherent to HAART (N=128) N (%)	Non-adherent to HAART (N=26) N (%)
Age: mean (SD)	44.14 (6.74)	44.07 (6.22)	44.46 (9.03)
Race/ethnicity: African American	144 (94.74)	119 (94.44)	25 (96.15)
Education: $\geq 12^{\text{th}}$ grade	97 (62.99)	84 (65.63)	13 (50.00)
Income: >\$5,000 annual	103 (67.32)	86 (67.19)	17 (68.00)
Current drug use [#]	74 (48.05)	56 (43.75)	18 (69.23) *
Depressive symptoms (CES-D>20)	51 (33.12)	40 (31.25)	11 (42.31)
Favorable attitudes about HAART: mean (SD)	16.80 (3.00)	17.01 (2.81)	15.77 (3.61) *
Comfortable taking HAART in the presence of close friends: Yes	101 (65.58)	91 (71.09)	10 (38.46) **
Comfortable taking HAART in the presence of close family: Yes	123 (79.87)	105 (82.03)	18 (69.23)
No. of kin in support network: mean (SD)	2.31 (2.10)	2.36 (2.14)	2.08 (1.90)
No. of friends in support network	2.59 (2.86)	2.66 (3.00)	2.27 (2.32)
Has a main partner	78 (50.65)	67 (52.34)	11 (42.31)
Has informal care: yes	126 (81.82)	110 (85.94)	16 (61.54) **
Reciprocity of support: Mean (SD)	9.23 (2.90)	9.48 (2.77)	7.86 (3.30) *
Negative support: Mean (SD)	6.55 (2.59)	6.47 (2.41)	7.57 (3.21) *

[#] In the prior 6 months

* p<.05,

** p<.01

Table II

Adjusted odds of HAART adherence among men in the ARK study (Baltimore, MD, U.S.; 2002-05; n = 154).

Independent variables	Model 1 (without interaction term)	Model 2 (with interaction term)
	Adjusted odds ratios	Adjusted odds ratios
Current illicit drug use [#]	0.45	0.61
Favorable attitudes about HAART	1.06	1.08
Comfortable taking HAART in the presence of close friends	2.73 *	2.90 *
Reciprocity of support: high	1.34	0.20
Has informal care: yes	2.93	0.83
Reciprocity of support X Has informal care	-----	12.14 *

[#] In the prior 6 months

* p<.05