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Social support as a predictor of early diagnosis, linkage, retention, and adherence to HIV care: Results from the Steps Study

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Abstract

Social support predicts adherence to antiretroviral therapy (ART) in some settings but has not been well studied in persons newly diagnosed with HIV infection as a predictor of success through the cascade of HIV care. One hundred sixty-eight persons newly diagnosed with HIV completed the Medical Outcomes Study Social Support Survey at diagnosis, and 129 were successfully followed for more than 12 months. Outcomes were earlier diagnosis of HIV infection, linkage to care, retention in care, ART use by 1 year, and adherence to ART. Higher social support scores (either overall or on a subscale) were associated with earlier HIV diagnosis, timely linkage to care, and adherence to ART. Social support did not predict use of ART or retention in HIV care. Success navigating some of the steps of HIV care is more likely with social support, but it is not sufficient to ensure success across the continuum of care.

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Conflict of Interest Statement

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Keywords

adherence; HIV; public health; retention in care; social support

Lack of social support may be an important barrier to HIV care because persons living with HIV infection (PLWH) must navigate complex care processes to achieve optimal outcomes. PLWH must be diagnosed as early as possible, linked to HIV care, retained in care, prescribed antiretroviral therapy (ART), and adhere to ART. This “steps of HIV care” model for maximizing outcomes in HIV infection (Giordano, Suarez-Almazor, & Grimes, 2005) is similar to the HIV treatment cascade model (Gardner, McLees, Steiner, Del Rio, & Burman, 2011), both of which succinctly capture the continuum of care that patients must navigate. One could reasonably expect that social support would impact one’s motivation and ability to access HIV testing, attend appointments, accept ART, obtain medication refills, and adhere to ART.

For some steps in the care process, the link between social support and success in navigating the continuum is more than speculative. Lack of social support has been associated with a lower level of adherence to ART (Atkinson, Schonnesson, Williams, & Timpson, 2008; Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Murphy, Marelich, Hoffman, & Steers, 2004). There is also evidence to support a direct relationship between tangible support (i.e., someone who helps a person obtain medication refills) and adherence to ART (Gonzalez et al., 2004; Ulett et al., 2009; Vyavaharkar et al., 2007). Social support has also been targeted as a means to improve adherence, with mixed results (Carrico et al., 2006; Jones et al., 2003; Jones et al., 2007; Levine et al., 2005). A study conducted in San Francisco identified a population with poor adherence and provided them with HIV-treatment specific support (Taylor, Neilands, Dilworth, & Johnson, 2010). They found no change in overall social support or adherence to ART. On the other hand, a study of women with AIDS in Miami, New York, and New Jersey in the United States found that, after a 10-session cognitive-behavioral stress management/expressive supportive therapy intervention on adherence to ART, a subgroup of low adherers significantly increased their mean self-reported adherence (Jones et al., 2003). In Uganda, a randomized controlled trial of a treatment supporter initiative intervention found that participants with treatment supporters had four times the odds of achieving optimal adherence to ART as compared to participants without a treatment supporter (Kunutsor et al., 2011). Social support likely influences adherence and appears to be a viable target for improving adherence, possibly beyond removing structural barriers to adherence (i.e., help picking up medications).

There is some evidence that social support impacts linkage to HIV care after diagnosis (Anthony et al., 2007). For example, limited social interactions (e.g., not having someone to enjoy life with) have been associated with delays in HIV care (McCoy et al., 2009). Likewise, the Antiretroviral Treatment Access Study (ARTAS), a two-arm randomized intervention study conducted in Atlanta, Baltimore, Miami, and Los Angeles, found that seeing a health care provider was significantly more likely among participants who reported at baseline that someone (a friend, family member, social worker, or other person) was helping them get into care (Gardner et al., 2005). On the other hand, the degree of social

support of HIV-infected crack users was not associated with linkage to care (Bell et al., 2010). Thus, the relationship between social support and linkage to care is not firmly established.

Few studies have evaluated the impact of social support in patients newly diagnosed with HIV infection (Bell et al., 2010; McCoy et al., 2009). No study has prospectively studied the impact of social support on success in navigating the full HIV care continuum or steps of HIV care in persons newly diagnosed with HIV infection. The importance of each step is recognized by U.S. national priorities, including the Centers for Disease Control and Prevention's promotion of expanded HIV testing (Branson et al., 2006), the National HIV/AIDS Strategy's goals related to linkage to care and retention in care (The White House Office of National AIDS Policy, 2010), the U.S. Department of Health and Human Services (DHHS) HIV treatment guidelines that recommend treatment regardless of CD4+ T cell count (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2013), and the International Association of Providers of AIDS Care (IAPAC) adherence guidelines that recommend adherence support to maximize virologic suppression (Thompson et al., 2012). Given the importance of the steps of HIV care and evidence supporting social support's impact on some steps, we hypothesized that greater social support at the time of HIV diagnosis would be associated with earlier diagnosis of HIV, and that greater social support would predict successful linkage to and retention in HIV care, more ART initiation, and higher adherence to ART.

Between 2006 and 2009, we conducted the Steps Study, a prospective observational cohort study of persons newly diagnosed with HIV infection designed to provide insight on baseline predictors of success following the steps of HIV care (Bhatia, Hartman, Kallen, Graham, & Giordano, 2011; Graham et al., 2013). We herein report on analyses of that dataset examining whether perceived social support in persons newly diagnosed with HIV infection predicts success with the steps of HIV clinical care. If social support predicted success navigating the steps of HIV care, health providers could measure social support at diagnosis, and provide appropriate interventions to maximize treatment outcomes.

Method

Participants

The Attitudes and Beliefs and the Steps of HIV Care study (the Steps Study) was a prospective observational cohort study of persons newly diagnosed with HIV infection in a southeast Texas metropolitan area. To be eligible, potential participants had to be diagnosed with HIV infection within the previous 90 days and not yet have completed a scheduled outpatient visit with an HIV primary care provider. Participants were enrolled from January 2006 to September 2007 from the site of HIV diagnosis. Sites of recruitment were inpatient and outpatient public facilities primarily serving uninsured and underinsured populations. The target sample size was 200 participants. Additional details of the study are published elsewhere (Bhatia et al., 2011; Graham et al., 2013).

Procedures and Measures

Participants completed structured interviews at enrollment and every 3 months for up to 18 months of follow-up. The baseline interview included demographic characteristics (see Table 1) and the Medical Outcomes Study Social Support Survey (MOS-SSS; Sherbourne & Stewart, 1991). The MOS-SSS is a well-validated 19-item measure that describes perceived functional support as overall social support. The scale includes four sub-domains: emotional support (8 items), tangible support (4 items), affectionate support (3 items), and support through positive social interaction (3 items). Scores can range from 0 to 100, and in a general U.S. population, the mean overall score is 70.1 (SD = 24.2), with subscale scores ranging from 69.6 to 73.7 (Sherbourne & Stewart, 1991). The follow-up surveys included items measuring appointments attended, ART use, and adherence to ART. Adherence was assessed with an instrument based on a visual analogue scale that reflected the previous 4 weeks of ART medication adherence (Giordano, Guzman, Clark, Charlebois, & Bangsberg, 2004). All self-reported health care use and ART use was confirmed by medical record review. CD4+ T cell count and HIV viral load data were also gathered from medical record review.

Outcomes

Outcomes included early HIV diagnosis, linkage to care, retention in care, ART initiation, and adherence to ART. Early HIV diagnosis was defined as an initial CD4+ T cell count equal to or greater than 200 cells/mm³, given that a lower CD4+ T cell count is diagnostic of AIDS, a mark of delayed diagnosis (Swindells et al., 2011). Linkage to care was defined as having completed at least one outpatient visit for HIV primary care within 90 days of diagnosis (The White House Office of National AIDS Policy, 2010). Retention in care was defined as having completed at least one visit for HIV primary care in each of 3 or 4 quarter-years in the year after diagnosis (Giordano et al., 2007). Based on treatment recommendations at the time (Department of Health and Human Services [DHHS] Panel on Clinical Practices for Treatment of HIV Infection, 2005), ART initiation within 1 year of diagnosis was assessed for patients with a baseline CD4+ T cell count less than 350 cells/mm³ and was dichotomized. Adherence to ART was assessed by average responses on the visual analogue scale (VAS) using all available follow-up reports for the participant, which provided a more reliable estimate for each participant (see, for example, Bangsberg, Ragland, Monk, & Deeks, 2010). The adherence score was then dichotomized at equal to or greater than 95% or less than 95% (Giordano et al., 2004).

Data Analysis

For the present analyses, participants were censored at last contact with the study or with the health care system, whichever was later. Because CD4+ T cell count was critical to measuring early diagnosis and receipt of ART, persons with missing baseline CD4+ T cell counts were excluded from the present analysis. Social support scores were standardized to a 0–100 scale. The means and standard deviations (SD) of the overall and subscale scores were calculated, and Student's t-test was used to compare scores of the groups that achieved and did not achieve each of the outcomes. Multivariate logistic regression models of the outcomes adjusted for age, race/ethnicity, marital status, income, employment, and sexual

orientation. Social support scores were entered into the models as dichotomous variables split at 50, representing high or low social support. A score of 50 represented approximately one standard deviation below the population mean for overall social support, which, we reasoned, indicated substantially low social support (Sherbourne & Stewart, 1991). A separate model was created for each social support subscale and each outcome if the association in univariate analysis was $p < 0.20$. The initial model included all of the control variables, and the final model retained control variables significant at the $p = 0.20$ level or lower. We considered p values < 0.05 to be statistically significant and $p < 0.10$ to be indicative of a trend.

Human Subjects

The Institutional Review Board for Baylor College of Medicine and Affiliated Institutions approved this study. All subjects provided written informed consent.

Results

Participants

We screened 239 newly diagnosed PLWH in order to enroll 200 participants, our target enrollment. The 39 preliminarily eligible persons who declined enrollment did not significantly differ from the 200 enrolled in their age, sex, race/ethnicity and site of enrollment (the only variables we could gather on the non-enrolled population). Of the 200 enrolled participants, subsequent detailed medical record review showed that 11 enrollees were not, in fact, eligible, and were removed from the study for the following reasons: false-positive rapid HIV test result ($n = 5$), more than 90 days since HIV diagnosis ($n = 4$), and had already completed an outpatient HIV provider visit ($n = 2$). Of the 189 remaining participants, one immediately transferred care outside of Houston and could not be followed, three withdrew consent, and one died before baseline surveys were completed. The MOS-SSS was completed by 178 of the 184 remaining participants, and 168 of 178 participants had a baseline CD4+ T cell count result. The baseline characteristics for 168 participants in the present analysis are presented in Table 1.

Nearly a third of the participants were female, 50.6% of the participants identified themselves as African American, while 39.9% identified themselves as Hispanic. Fifty-three percent of the participants were between the ages of 31 and 50 years, 52.4% of the participants were not employed, and 86.1% had an annual income less than \$25,000. About two thirds of the participants were living alone, and 70.8% identified themselves as heterosexual.

Social Support

The mean (SD) overall social support score was 65.1 (25.3). The mean (SD) scores for subscales were as follows: 59.6 (28.8) for emotional social support; 68.8 (28.3) for tangible social support; 71.9 (32.2) for affectionate social support; and 64.6 (32.5) for positive social interaction social support.

Outcomes and Their Associations With Social Support

Of the 168 participants, 85 were diagnosed with a CD4+ T cell count ≥ 200 cells/mm³ (50.6%) and 142 were linked to care (84.5%). Of the 129 participants who were not lost to follow-up to the study before 1 year, 90 were retained in HIV medical care (69.8%). Regarding use of ART, 115 participants had a baseline CD4+ T cell count < 350 cells/mm³, so they were expected to be started on ART according to treatment guidelines at the time (DHHS Panel on Clinical Practices for Treatment of HIV Infection, 2005), and 92 were initiated on ART (80.0%). Six participants initiated ART with a CD4+ T cell count > 350 cells/mm³, and of the 98 participants on ART, 54 self-reported an average adherence to ART $\geq 95\%$ (55.1%).

As shown in Table 2, overall social support, positive social interaction social support, and affectionate social support scores were higher in participants with earlier diagnoses (i.e., CD4+ T cell counts ≥ 200 cells/mm³ at diagnosis). There were no statistically significant associations at $p < 0.05$ between overall social support and linkage to care, although mean tangible support subscale scores tended to be higher for participants linked to care within 90 days ($p = 0.06$). Baseline overall social support scores and subscale scores did not predict retention in care or receipt of ART. Baseline tangible social support scores were higher in participants who subsequently had at least 95% adherence to ART ($p = 0.04$), and affectionate social support scores tended to be higher in the more adherent participants ($p = 0.08$).

Multivariate logistic regression models were constructed to adjust for baseline characteristics to assess the independent association of high or low social support with the outcomes. Similar to Student *t* test results, findings at the $p < 0.10$ level were noted for the effect of social support on early diagnosis, linkage to care, and adherence to ART (Table 3). Positive social interaction social support scores greater than 50 (OR 2.86, $p < 0.01$) and affectionate social support scores greater than 50 (OR 2.08, $p = 0.06$) were associated with CD4+ T cell counts ≥ 200 cells/mm³ at diagnosis. Affectionate social support scores greater than 50 (OR 2.32, $p = 0.07$) and tangible social support scores greater than 50 (OR 2.55, $p = 0.04$) predicted successful linkage to care. For adherence to ART, overall social support scores greater than 50 (OR 2.36, $p = 0.05$) and tangible social support scores greater than 50 (OR 3.01, $p = 0.02$) predicted adherence equal to or greater than 95%. Because there were no findings at the $p \leq 0.20$ level in univariate analyses for receipt of ART or retention in care, multivariate models were not created.

Discussion

We studied the perceived social support of 168 persons newly diagnosed with HIV infection to determine if greater social support at the time of HIV diagnosis was associated with earlier diagnosis, and if greater social support predicted successful linkage to and retention in HIV care, more ART initiation, and greater adherence to ART. Our review of the literature suggested that no single study had examined these relationships, especially in persons newly diagnosed with HIV infection. We hypothesized that greater support would result in more success. We found some evidence to support our hypothesis, but the results were mixed.

Overall social support was only predictive of earlier HIV diagnosis (i.e., higher baseline CD4+ T cell count). Highly significant findings within the affectionate and positive interaction support sub-scales likely drove the results for overall social support. To some extent, perceived social support manifests in a network of people, a measure of structural social support. We did not design our study to understand who the supporter(s) might be, but other studies have attempted to map the social networks of persons newly diagnosed with HIV infection and use these networks as active case-finding strategies (Centers for Disease Control and Prevention, 2005; Kimbrough et al., 2009). Active case-finding strategies are more likely to fail with smaller networks or networks that did not include PLWH (Kimbrough et al., 2009). Our results add to these findings and suggest that participants' functional social isolation contributes to delayed diagnosis.

We found that tangible social support tended to predict successful linkage to care, consistent with some prior literature (McCoy et al., 2009), including the ARTAS, a two-arm randomized intervention study conducted in Atlanta, Baltimore, Miami, and Los Angeles. In particular, participants in that study who reported at baseline that someone (a friend, family member, social worker, or other person) was helping them get into care were significantly more likely to see a health care provider (Gardner et al., 2005). We measured social support more completely than ARTAS, but similarly found that only tangible social support tended to predict timely linkage to care.

More social support, particularly tangible support and to a lesser extent affectionate support, predicted higher adherence to ART in our study. Tangible support could be, for example, someone who reminds an HIV-infected person to take ART or helps a person obtain medication refills. The association of tangible support with adherence to ART was consistent with prior studies, including studies from the developing world (Gonzalez et al., 2004; Ulett et al., 2009; Vyavaharkar et al., 2007).

Our findings on the influence of social support with both adherence and linkage to care in a prospective cohort support previous literature and lend credibility to our positive findings related to early diagnosis as well as to our negative findings on receipt of ART and retention in care. The data in Table 2 suggest that the negative findings for receipt of ART and retention in care were probably not related to sample size: none of the 10 *p* values for those two outcomes was ≤ 0.20 , in contrast to 11 of the 15 *p* values for early diagnosis, linkage to care, and adherence to ART. That social support did not predict retention in care was particularly surprising because unmet needs predict poorer retention in care (Rumptz et al., 2007), and social support could reduce unmet needs. Further research should more completely assess functional social support and consider alternate ways of measuring retention in care (Mugavero et al., 2012).

Our study had several limitations. First, the MOS-SSS may be a well-validated tool, but it measures perceived social support, which may not reflect actual functional social support. Furthermore, there are no standardized cut-points for analyzing MOS-SSS data, limiting cross-study comparisons. The study did not include an HIV-uninfected control group. A number of participants were lost to follow-up, which may have affected our results. However, the mean overall social support score was 65.0 for the 168 persons included in the

delayed diagnosis and linkage to care analyses, 66.5 for the 129 persons in the retention in care analysis, 63.0 for the 115 persons in the receipt of ART analysis, and 63.5 for the 98 persons in the adherence analysis. These similar means suggest that excluding persons from some of the analyses because of missing data was unlikely to affect the results. We conducted a number of comparisons and type I errors were possible. Finally, our study was conducted in a major metropolitan area in the southern United States, and may not be generalizable to other populations.

In this prospective observational cohort study of persons newly diagnosed with HIV infection, we found that greater social support may encourage earlier diagnosis, successful linkage to care, and higher adherence to ART. Our results suggest, however, that perceived social support may have a limited role in promoting receipt of ART and retention in HIV care, which are critical elements in the continuum of HIV care. Success navigating all the steps of HIV care will require interventions targeting more than just social support.

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Key Considerations

- Persons who are at high risk for HIV may have low levels of social support and should be encouraged to engage in regular testing so that HIV can be diagnosed at higher CD4+ T cell counts.
- Persons newly diagnosed with HIV infection may have low levels of tangible social support. At the time of diagnosis, clinical and social services staff should address barriers to linkage to HIV care, including social support.
- Social support should be assessed when trying to problem solve poor adherence, and strategies to overcome barriers to social support should be addressed.
- Although social support is a potential barrier to all aspects of HIV care, we found no evidence that social support impacted initiation of ART or retention in HIV care. Nurses should continue to encourage patients with HIV infection to use the full array of nursing, social work, case management, and clinical services available.

Table 1

Baseline Characteristics of 168 Participants in the Steps Study

Characteristic	Frequency	Percent
Gender (<i>n</i> = 168)		
Male	116	69.1
Female	52	30.9
Race/ethnicity (<i>n</i> = 168)		
African American (non-Hispanic)	85	50.6
Hispanic	67	39.9
White (non-Hispanic)	16	9.5
Age (<i>n</i> = 168)		
18–30 years	52	30.9
31–50 years	89	53.0
> 50 years	27	16.1
Employment status (<i>n</i> = 168)		
Employed	80	47.6
Not employed	88	52.4
Annual household income (<i>n</i> = 165)		
\$0–\$24,999	142	86.1
\$25,000 and above	23	13.9
Marital status (<i>n</i> = 167)		
Married or in a marriage-like relationship	52	31.1
Not married or in a marriage-like relationship	115	68.9
Sexual identity (<i>n</i> = 168)		
Heterosexual	119	70.8
Not heterosexual	49	29.2

Table 2

Mean Medical Outcomes Study Social Support Survey Scores and Sub-scale Scores Predicting Outcomes Among Participants in the Steps Study

Outcome	Overall Social Support (Mean, SD)	Emotional Social Support (Mean, SD)	Tangible Social Support (Mean, SD)	Affection Social Support (Mean, SD)	Positive Interaction Social Support (Mean, SD)
Early Diagnosis (<i>n</i> = 168)	(<i>p</i> = 0.01)	(<i>p</i> = 0.15)	(<i>p</i> = 0.57)	(<i>p</i> < 0.01)	(<i>p</i> < 0.01)
CD4+T < 200 cells/mm ³ (<i>n</i> = 83)	60.1 (27.1)	56.3 (30.1)	67.5 (29.0)	64.3 (36.2)	54.4 (34.3)
CD4+T ≥ 200 cells/mm ³ (<i>n</i> = 85)	69.8 (22.5)	62.8 (27.3)	70.0 (27.7)	79.5 (25.7)	74.6 (27.3)
Linked to Care (<i>n</i> = 168)	(<i>p</i> = 0.13)	(<i>p</i> = 0.40)	(<i>p</i> = 0.06)	(<i>p</i> = 0.20)	(<i>p</i> = 0.31)
Yes (<i>n</i> = 142)	66.3 (24.8)	60.4 (28.9)	70.5 (27.5)	73.3 (31.5)	65.7 (32.4)
No (<i>n</i> = 26)	58.1 (27.4)	55.1 (28.4)	59.4 (31.4)	64.4 (35.6)	58.7 (33.1)
Retained in Care (<i>n</i> = 129)	(<i>p</i> = 0.79)	(<i>p</i> = 0.64)	(<i>p</i> = 0.85)	(<i>p</i> = 0.40)	(<i>p</i> = 0.24)
Yes (<i>n</i> = 90)	66.1 (25.3)	60.7 (29.1)	70.4 (28.8)	72.4 (32.6)	64.9 (31.7)
No (<i>n</i> = 39)	67.4 (24.5)	58.1 (28.9)	69.4 (27.9)	77.6 (29.7)	72.1 (32.4)
ART use (if baseline CD4+T < 350 cells/mm ³ ; <i>n</i> = 115)	(<i>p</i> = 0.87)	(<i>p</i> = 0.82)	(<i>p</i> = 0.39)	(<i>p</i> = 0.48)	(<i>p</i> = 0.71)
Yes (<i>n</i> = 92)	63.2 (25.6)	58.0 (28.5)	70.6 (27.9)	67.8 (35.3)	59.7 (33.5)
No (<i>n</i> = 23)	62.1 (27.7)	56.4 (30.1)	64.9 (28.0)	73.6 (32.5)	62.7 (36.3)
Adherence to ART (if on ART; <i>n</i> = 98)	(<i>p</i> = 0.12)	(<i>p</i> = 0.28)	(<i>p</i> = 0.04)	(<i>p</i> = 0.08)	(<i>p</i> = 0.11)
95–100% (<i>n</i> = 54)	67.5 (27.1)	61.1 (31.1)	75.0 (28.1)	74.5 (32.7)	67.1 (32.4)
< 95% (<i>n</i> = 44)	58.6 (28.2)	54.4 (30.1)	62.4 (31.7)	61.7 (37.9)	55.9 (35.7)

Note. ART = antiretroviral therapy; **Bold** = *p* < 0.10 (indicative of a trend).

Table 3

Multivariate Modeling Results of Medical Outcomes Study Social Support Survey Scores and Sub-scale Scores Predicting Outcomes Among Participants in the Steps Study

Outcome	Overall Social Support Score > 50	Tangible Social Support Score > 50	Affection Social Support Score > 50	Positive Interaction Social Support Score > 50
Early Diagnosis (CD4+ 200 cells/mm ³ ; n = 168)				
Odds ratio			2.08	2.86
95% CI			(0.98, 4.55)	(1.47, 5.56)
P value			0.06	< 0.01
Linked to Care (n = 168)				
Odds ratio		2.55	2.32	
95% CI		(1.04, 6.23)	(0.94, 5.70)	
P value		0.04	0.07	
Adherence to ART 95% (if on ART; n = 98)				
Odds ratio		2.36	3.01	
95% CI		(0.99, 5.58)	(1.19, 7.95)	
P value		0.05	0.02	

Note. ART = antiretroviral therapy. Only results with $p < 0.10$ are presented. Because there were no associations at the $p = 0.20$ level in univariate analyses for receipt of ART or retention in care, multivariate models were not created. There were no significant findings at $p < 0.10$ for emotional social support. Variables considered for each model included sex, race/ethnicity, age, employment status, household income, marital status, and sexual identity.