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Social Networks of Substance Users With HIV Infection: Application of the Norbeck Social Support Scale

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Abstract

The role of social support networks in medication adherence among HIV-infected substance users remains understudied. In this secondary data analysis, the authors sought to determine the relationship between social support networks and antiretroviral adherence among HIV-infected substance abusers receiving methadone. They analyzed data collected in a 24-week study of 76 methadone-maintained, HIV-infected substance abusers randomized to directly observed antiretroviral therapy or treatment as usual. The authors used logistic regression to examine the relationship between social support networks and self-reported antiretroviral adherence. Their results showed that study participants had an average of 1.36 social network members ($SD = 1.4$); 34% of participants had at least one drug user and 25% had at least one HIV-infected person in their network. The presence of network drug users and HIV-infected network members was associated with less antiretroviral medication adherence ($p < .05$). The authors conclude that both social network density and characteristics of network members have implications for medication adherence.

Keywords

social support; social networks; Norbeck Social Support Scale; HIV positive; substance use

The social support provided by social networks has been shown to have a positive influence on health outcomes in many populations (Heaney & Israel, 2002). A variety of studies have found that sound social support and the presence of social networks were important factors in managing disease, utilizing health services appropriately, and maintaining hope during periods of ill health (Pimouguet, Le Goff, Thiebaut, Dartigues, & Helmer, 2011; Rosland & Piette, 2010). Understanding social support and social networks may be particularly valuable in working with certain vulnerable populations, such as substance abusers, where limitations in economic resources may not necessarily mean limitations in social resources such as extended family and friends. Social support has been an important variable in health services research (Kouzis & Eaton, 1998). Thus, interventions to enhance social resources may provide cost-effective and/or feasible pathways to enhance health behaviors and outcomes.

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Social Support and Its Measurement

Social networks encompass the number and depth of an individual's social relationships. This “web of social relationships that surround individuals” can be characterized by demographic, geographic, and interaction variables (Heaney & Israel, 2002, p. 190). Social support is a key component of social networks and has historically been broken into four types: emotional (provision of love), instrumental (concrete services), informational, and appraisal (self-assessment; House, 1981). The depth and composition of a social network influence the quality and quantity of social support that a person receives.

The importance of social support in HIV treatment adherence has been studied in international populations with samples made up mainly of heterosexual women and men (Baek & Rutenber, 2010; Ncama et al., 2008). Domestically, social support has been found to be an important factor in HIV adherence in samples of gay men, older adults, and high-risk adolescents (Abramowitz et al., 2009; Johnson, Heckman, Hansen, Kochman, & Sikkema, 2009; Wrubel, Stumbo, & Johnson, 2008). In studies with samples of substance users with HIV infection, greater social support has also been associated with better antiretroviral adherence, but little is known about the precise relationship between social networks and medication adherence or about how specific interactions between social support and social networks affect health behaviors (Malta, Magnanini, Strathdee, & Bastos, 2008).

Some of the instruments assessing social support, although well validated, may not have been able to capture important interactions affecting health behavior in specific populations. For example, in their work with medication adherence in HIV-infected substance abusers, Knowlton and colleagues used either a one- or two-item instrument with a 4-point response scale asking how certain a person was that they had someone to talk to about personal and private things (Knowlton et al., 2006) or to take care of them if they were sick (Knowlton et al., 2007). Kerr and colleagues (2004), in an adherence study with injection drug users, used the Medical Outcomes Study Questionnaire, a 19-item scale on perceived availability of functional support (Sherbourne & Stewart, 1991). An alternative to these measures of social support, the Norbeck Social Support Scale Questionnaire (NSSQ), adds depth to our understanding of this construct by looking at specific forms of social support. The NSSQ contains subscales on affective, affirmative, and concrete support, in addition to an assessment of the quantity and specific contributions from network members (Norbeck, Lindsey, & Carrieri, 1981). This combination of measures of both quality and density of networks allows the development of a comprehensive understanding of social support. However, no studies were identified in which the NSSQ was used as a predictor of medication adherence in a population of HIV-infected substance abusers.

Purpose

The purpose of this study was to describe the social support networks of a sample of HIV-infected men and women attending an urban methadone maintenance program and to determine the relationship between social networks and HIV medication adherence. We hypothesized that the type, amount, and source (drug user and HIV-infected person) of social support at baseline was associated with future medication adherence.

Method

Study Design

To conduct this secondary data analysis, we used data from the Support for Treatment Adherence Research Through Directly Observed Therapy (STAR*DOT) study (Berg,

Litwin, Li, Heo, & Arnsten, 2011), a randomized trial of the efficacy of an antiretroviral DOT program in methadone maintenance clinics. The STAR*DOT study was a 24-week long trial conducted in a network of 12 methadone maintenance clinics in Bronx, New York, from 2004 to 2007. The clinics, administered by Albert Einstein College of Medicine and Montefiore Medical Center, provide care to approximately 4,000 clients, of whom 10% to 15% are HIV infected. The STAR*DOT study, including participant safety, randomization, enrollment, follow-up, and laboratory procedures, has been described in detail elsewhere (Berg et al., 2011). All participants gave written informed consent. The Committee on Clinical Investigations of the Albert Einstein College of Medicine and the Institutional Review Board of Montefiore Medical Center provided approval of the parent study.

Data Collection Procedures

Data were collected through an audio computer-assisted self-interview (ACASI) in which participants used head phones to listen to questions and simultaneously read the text on a screen. After hearing and reading each question, participants used a touch screen to tap in their selections directly on the computer screen. ACASI technology automatically populated a database as each participant answered questions. All interviews were administered one at a time in a private office inside the methadone clinics. A research assistant was available in the room to answer any questions during the interviews.

Measures

The major independent variable was current social support, assessed at baseline with the NSSQ (Norbeck et al., 1981). The NSSQ has been used to provide a nuanced picture of the relationship between health outcomes and both social support and social networks in a wide variety of populations (Norbeck et al., 1981). These have included Chinese patients following cancer surgery (Chan, Hon, Chien, & Lopez, 2004), adult survivors of physical or sexual abuse (Muller & Lemieux, 2000), low-income prenatal patients (Schaffer & Lia-Hoagberg, 1997), African American adolescents with asthma (Sin, Kang, & Weaver, 2005), and patients waiting for cardiac transplants (Hirth & Stewart, 1994).

To complete the NSSQ, participants listed the names of people who provided them with personal support and their relationship to that person. They then used a 5-point Likert-type scale response format, with possible choices ranging from 0 (*not at all*) to 4 (*a great deal*), to answer eight questions about the amount of support available from each of the names on their list, with higher scores indicating greater support. Using ACASI as a data collection method allowed the individual responses for each question to be read aloud and then read aloud again for each of the follow-up questions (e.g., Question 1: "Please list the names of 10 people who . . ." Response: "X" and "Y." Follow-up Questions: "In Question 1, you said that 'X' was able to help you . . . How much did 'X' help you . . .?" "In Question 1, you said that 'Y' was able to help you. How much did 'Y' help you . . .?").

The NSSQ measures several domains of social support:

Affective or emotional support—It was assessed with two items about each person mentioned as a source of support ("How much does this person make you feel liked or loved?" and "How much does this person make you feel respected or admired?").

Affirmative support—It was assessed with two items about each person ("How much can you confide in this person?" and "How much does this person agree with or support your actions or thoughts?").

Concrete support—It was assessed with two items about each person (“If you needed to borrow US\$10, a ride to the doctor, or some other immediate help, how much could this person usually help?” and “If you were confined to bed for several weeks, how much could this person help you?”).

The items in each of these three domains had high Pearson correlations (.97, .96, and .89, respectively) and good test–retest reliability (.89, .88, and .86, respectively) in the original evaluation of these instruments (Norbeck et al., 1981).

A *total support* score was generated by summing the responses to the six affective, affirmative, and concrete support items. The overall *network properties* were determined by asking the nature and duration of each relationship and the frequency of contact for each person mentioned as a source of support. For this study, we added three items asking whether each person mentioned as a source of support was a drug user, was HIV infected, or knew of the participant's HIV status, though these three additional items were not included in the *total support* score. Finally, a *total loss* score was calculated by asking each participant whether they had lost any important relationships in the past year, with responses in a simple “yes/no” format.

The dependent variable, antiretroviral adherence, was assessed through self-report over the past 7 days at three time points, baseline, Week 12, and Week 24. The self-report instrument consisted of seven items on the number and timing of pills prescribed per day and the number missed yesterday, the day before, 3 days ago, and last week. This instrument was developed for use by the Adult AIDS Clinical Trials Group and has been widely used both domestically and internationally (Chesney et al., 2000). Although a variety of instruments and methods are available to assess adherence, ease of administration makes self-report measures ideal for use in clinical trials (Malta et al., 2008). The results correlate well between the many studies using self-report measures and also with viral load assessed on the day of survey completion in general and in the parent STAR*DOT study (Berg et al., 2011; Chesney et al., 2000). Adherence was dichotomized as either 100% (no missed doses or pills any time in the past week) or <100% because, in contrast to current clinical guidelines, those at the time stressed the need for complete adherence for optimal health outcomes and suppression of viremia (American Public Health Association, 2004; Department of Health and Human Services, 2011).

To characterize the sample and to examine other potential contributors to adherence, the following sociodemographic variables were collected: age, gender, race/ethnicity, education, employment, marital status, health insurance, homelessness in past 6 months, incarceration history, perceived health status, duration of HIV infection, number of years on methadone maintenance, and drug and alcohol use in the past 30 days (Arnsten et al., 2002; Derogatis & Spencer, 1982; Maisto & Saitz, 2003; McLellan, Luborsky, Woody, & O'Brien, 1980; Purcell et al., 2004; Wu, Revicki, & Malitz, 1997).

Analysis

Descriptive statistics were generated to present baseline demographic and social support network characteristics of participants. We used a repeated cross-sectional design with social support measured at baseline and adherence measured at three time points: baseline, 12 weeks, and 24 weeks. We conducted bivariate analyses to examine associations between each of the social support variables (described above) and self-reported 7-day adherence at each time point. We then constructed three separate logistic regression models to test the independent relationships between the social support variables (number of significant people in one's network, the Norbeck “total network score,” Norbeck “total support score,” and Norbeck “total loss score”) as well as the relationships between the three added questions

(was support person a drug user, was support person HIV infected, and did support person know of the participant's HIV status) and adherence at each of the three time points: baseline, Week 12, and Week 24 follow-up. All models were controlled for age, gender, race/ethnicity, and STAR*DOT intervention effect. SAS 9.2 was used for all analyses. Missing data were dropped from the analysis when the logistic regression model was built. A power calculation was not conducted for this secondary data analysis because of the small sample size and the unknown effect size.

Results

The study population was made up of 76 participants, with data available for 64 (84.2%) at Week 12 and for 65 (85.5%) at Week 24. The population was largely middle aged (average = 47 years, $SD = 7$, range = 33-61) and included both males (54%) and females (46%). Participants were minimally educated (49% had less than a high school education) and largely unemployed (97%). Fewer than half (43%) were married or living with a partner. Participants had been HIV infected for an average of 13 years (range = 2-17) and had been in methadone maintenance for an average of 11 years (range = 5-16). All were on highly active antiretroviral therapy. Almost all (92%) had an antiretroviral drug regimen of more than one pill a day, and 72% had a medication dosing frequency of two or more times a day. More than half of the participants (62%) perceived their health to be good, very good, or excellent. Baseline characteristics of the sample are shown in Table 1.

Participants had a mean of 1.36 people in their social network ($SD = 1.4$, range = 0-7), a mean total support score of 26.57 ($SD = 29.27$, range = 0-167), and a mean total network score of 12.76 ($SD = 15.69$, range = 0-97). Drug users were included in 36% of participants' networks, and HIV-infected individuals were part of 25% of their networks. Among those providing social support, 16% were both drug users and HIV positive. The number of drug users in networks was highly correlated with participants' drug use. Other network characteristics are shown in Table 2. The frequent relationships of the 103 sources of social support reported by participants were friends (29, 28.2%), children (19, 18.5%), spouses or partners (16, 15.5%), mothers (12, 11.7%), and sisters (11, 10.7%; data not shown). Other relatives were mentioned as a source of support by 7 participants (6.8%), fathers and sex partners were each mentioned by 2 participants (1.9%), and brothers by one participant (1%). There were no differences in social support scores by race/ethnicity. Female participants had more people in their networks (1.71 vs. 0.85, $p < .0002$), higher overall social support (38.6 vs. 16.29, $p < .001$), and higher total network scores (19.03 vs. 7.41, $p < .001$) than male participants. There were no statistical differences in social support scores between participants who were retained when compared with those who dropped out at either of the two follow-up points.

In multivariate analysis, the odds of achieving 100% adherence (by 7-day self-report) were statistically lower among persons with certain social network characteristics. Specifically, participants with HIV-positive network members were significantly less likely to be adherent at baseline (odds ratio [OR] = 0.34, 95% confidence interval [CI] = [0.12, 0.95]) and at 12 weeks (OR = 0.2, 95% CI = [0.07, 0.64]; $p < .05$ for both comparisons), as were participants with drug users in their network at 24 weeks (OR = 0.22, 95% CI = [0.06, 0.82], $p < .05$; Table 3).

Discussion

Using the details provided by the NSSQ, we found no relationship between the social support scores and medication adherence. These findings do not support those of other researchers who found social support to be a contributor to adherence, albeit while using

alternative and less-specific measures of social support than that available from the NSSQ (Kerr et al., 2004; Knowlton et al., 2007). Although the sample sizes in other studies were larger ($n = 1,113$ and $n = 199$, respectively), it is intriguing to consider the implications of the use of a more robust assessment of social support that included social networks. The addition of extra questions about the composition of the social support specific to this population (i.e., inclusion of drug-using and HIV-positive network members) showed lower rates of HIV medication adherence among participants with HIV-positive members (at baseline and 12 weeks) and drug users (at 24 weeks) in their social networks, suggesting that not all social networks exert the same power.

The very small size of the networks of participants in this study provides a possible way to understand these results. The NSSQ was originally normed with more than 1,400 nursing students who had an average of 10 people in the networks, in comparison with the average of 1.36 in this sample (Norbeck et al., 1981). The original group had average total support and network scores greater than 170 and 95, in comparison with the 26.57 and 12.76 average respective scores of this sample. The confluence of small network size and low level of social support of these participants suggest a pathway for the negative influences of both HIV-positive and drug-using network members. For example, Weaver and colleagues (2005) found that low levels of social support were mediated by the avoidant coping strategies found in a sample of HIV-positive individuals. Active drug use has been found to be negatively associated with HIV medication adherence, and the inclusion of drug users in participants' support networks may serve as a proxy for individual drug use (Hinkin et al., 2007). Alternatively, drug users can trigger participants' drug use, which in turn, can negatively impact medication adherence and mitigate any possible positive effect of social support.

A limitation of the study was the small sample size that did not provide adequate power to assess changes in social support over time. This also shaped our hypothesis that baseline social support would have an effect on adherence over time. A larger sample size would be able to assess changes in social support and their impact on adherence. In addition, the mechanisms by which features of our participants' social support networks were supportive are still unclear. For example, we do not know *how* HIV-positive support members influence medication adherence in everyday interactions. Future qualitative studies would have to flesh these interactions out further. The possibility of recall bias in reporting adherence is an additional limitation, which is always present in studies relying on self-reports.

Improving our understanding of the role of social support networks in medication adherence with high-risk and vulnerable populations can have implications for the design of appropriate interventions. We suggest that the use of the NSSQ or other instruments that provide more nuanced understandings of social networks can provide researchers with a mechanism for increased understanding of this construct.

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Table 1**Baseline Characteristics of Participants ($N = 76$)**

Age, M (SD)	47.01 (6.89)
Male, n (%)	41 (53)
Race/ethnicity, n (%)	
Latino	35 (46)
Non-Latino Black	31 (40)
Non-Latino White and other non-Latino	11 (14)
Less than high school education, n (%)	38 (49)
Employed, n (%)	2 (3)
Marital status, n (%)	
Married/living with partner	34 (44)
Widowed/separated/divorced/single	43 (56)
Medicaid as primary insurance, n (%)	69 (90)
Stably housed, n (%)	56 (73)
Ever incarcerated, n (%)	45 (58)
Health status, n (%)	
Poor or fair	29 (38)
Good, very good, and excellent	47 (61)
Number of years living with HIV, M (SD)	12.75 (6)
Number of years on methadone maintenance, M (SD)	10.90 (8)
Substance use in past 30 days, n (%) self-report?	
Heroin	20 (26)
Cocaine	22 (29)
Crack	27 (35)
Hazardous alcohol use, n (%)	15 (19)
Antiretroviral dosing two or more times per day, n (%)	56 (73)
Self-reported 7-day antiretroviral adherence	
100%, n (%)	55 (72)
< 100%, n (%)	21 (27)

Table 2Support Network Characteristics ($N = 76$)

	Range	<i>M</i>	<i>SD</i>
Number of people in network	0-7	1.36	1.4
Affective support score	0-56	9.2	10.24
Affirmative support score ^a	0-55	8.76	9.84
Concrete support score ^a	0-56	8.61	9.41
Number of drug users as network members	0-3	0.39	0.61
Number of HIV-positive people as network members	0-2	0.28	0.51
Number of network members that know participants' HIV status	0-4	1.04	1.09
Total support members	0-17	26.57	29.27
Total network members	0-97	12.76	15.69
Total loss score	0-5	0.37	1.07

^a Scores based on number of network members multiplied by type of support given, based on a 5-point Likert-type scale ranging from 0 (not *at all*) to 4 (a *great deal*).

Table 3

Relationship Between Social Support Characteristics and Odds of Self-Reported 7-Day Adherence (100%)

Social Support Characteristics	Past 7-Day Adherence		
	Baseline (<i>N</i> = 76)	Week 12 (<i>n</i> = 64)	Week 24 (<i>n</i> = 65)
	OR [CI]	OR [CI]	OR [CI]
Number of people in network	1.3 [0.78, 2.17]	0.65 [0.35, 1.21]	0.84 [0.45, 1.58]
Total support people	1.02 [0.99, 1.04]	0.99 [0.96, 1.01]	0.99 [0.98, 1.02]
Total network people	1.03 [0.99, 1.08]	0.98 [0.93, 1.03]	0.99 [0.96, 1.03]
Total loss score	0.83 [0.62, 1.12]	1.07 [0.713, 1.60]	0.98 [0.95, 1.01]
Number of drug users as network members	0.86 [0.35, 2.11]	0.505 [0.156, 1.636]	0.227 [0.063, 0.820]
Number of HIV-positive people in network members	0.34 [0.12, 0.95]	0.22 [0.07, 0.64]	0.29 [0.06, 1.32]
Number of network members that know participants' HIV status	0.96 [0.573, 1.62]	0.53 [0.27, 1.04]	0.69 [0.38, 1.26]

Note: OR = odds ratio; CI = confidence interval. All models control for age, gender, race/ethnicity, and intervention group.