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Peer Support to Promote Medication Adherence Among People Living with HIV/AIDS: The Benefits to Peers

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Abstract

Since early in the AIDS epidemic, HIV-positive individuals have benefited from the services of peer support or buddy programs. However, little research has focused on the experience of the peer providing support. We conducted qualitative interviews with nine HIV-positive peers who had participated in an intervention designed to provide support to other HIV-positive individuals as one means of promoting antiretroviral therapy adherence. Analyses of the peers' common dialogue about their involvement in the study revealed four main themes: social acceptance, reciprocal support, personal growth and empowerment, and resistance and other challenges. Recommendations for future research and for implementing similar interventions in a health care setting are provided.

Keywords

HIV/AIDS; peers; social support; HAART; adherence

The psychosocial consequences of infection with HIV are far-reaching. Those diagnosed with HIV/AIDS have identified psychosocial stressors, such as the rejection by friends and family, lack of intimacy, social isolation, social stigma, and lack of acceptance (Serovich, Bruckner, & Kimberly, 2000). Like other stigmatized individuals, many people with HIV infection withdraw from social situations and leave themselves vulnerable to psychological distress (Kalichman, 1995). The loss of social intimacy often leads to disempowerment and diminished self-esteem. Empirical research has documented that HIV-positive individuals report feeling socially isolated (Schroeder et al., 2001; Kalichman, 1995).

A common method for addressing the psychosocial stressors associated with chronic illnesses such as HIV involves training peers, who share a diagnosis with the patient to

provide social support and other assistance. Gussow and Tracy (1978) explained the success of peers by citing their ability to provide: (1) a role model who reinforces the benefits of behaviors, (2) a resource for coping techniques and experiential knowledge, (3) a sounding board for strong effect that may be burdensome to family members, (4) training in how to normalize the required behaviors, and (5) low-key behavioral monitoring. Peer support capitalizes on the peers' potentially influential relationships and their ability to relate to the needs and concerns of the targeted group (Whittemore et al., 2000).

Research on the peer approach in other chronically ill populations has suggested that both the peers providing the support and the patients receiving the support experience benefits (Hamilton & Borstein, 1979; Whittemore et al., 2000; Wilson & Pratt, 1987; Antonucci & Israel, 1986). Most peer support research in the area of HIV has been limited to HIV-negative volunteers who have provided social support to HIV-positive individuals. Notably, the majority of HIV social support interventions have utilized volunteers who are white heterosexual women or gay men (Christensen et al., 1999; Maslanka, 1996; Claxton et al., 1998; Cassel & Ouellette, 1995). No studies we could locate have examined the psychological benefits for an HIV-positive peer providing the support.

The present study was part of a randomized controlled trial of a peer support intervention aimed at increasing antiretroviral medication adherence among people living with HIV/AIDS (Simoni et al., 2005; Simoni, Frick, & Huang, in press). The project took place at an out-patient infectious disease clinic in the Bronx, New York, that served primarily indigent African American and Latino individuals. In this qualitative substudy, we interviewed the peers in order to understand how their providing support may have affected them.

METHOD

Peer Intervention

Current clinic patients who were HIV-positive and on highly active antiretroviral therapy (HAART) served as "peers" or providers of support in the intervention. Medical providers in the clinic assisted study staff in identifying potential peers as those who reported consistently high levels of adherence, attended clinic appointments regularly, were socially skilled, and were able to participate in initial training and ongoing supervision. During training sessions, research staff trained the peers how to assess negative affective states and other barriers to adherence and to sensitively provide various types of social support. Other topics covered in the training included an overview of HIV and HAART, setting appropriate limits on the peer relationship, overcoming potential barriers to the acceptance of support, harm reduction approaches to substance use, making appropriate referrals for medical inquiries, and strategies for working with diverse participants. Peers received ongoing supervision (via twice-monthly group meetings and telephone calls) and were paid a small monetary incentive throughout their involvement.

The intervention consisted of two parts: twice-monthly one-hour group meetings at the clinic involving all peers and actively enrolled participants (i.e., "peer meetings"), in addition to weekly phone calls from peers to their assigned participants. In the group setting, participants were able to spend face-to-face time with their assigned peer as well as meet the

other peers and participants, with the goal of benefiting from the discussion of the shared experiences of the group. The primary themes of the meeting were identifying barriers to HAART adherence and problem-solving strategies to overcome them. Other themes that often emerged were life issues related to adherence, including HIV status disclosure, sexual and romantic relationships, substance use, and struggles with mental health issues. Research assistants coordinated the groups (e.g., arranged the room and provided refreshments) and facilitated discussion (e.g., refocused the discussion on adherence-related topics when appropriate) but otherwise refrained from interfering with the group process and the exchange of support among peers and participants. Between group meetings, peers were instructed to call each of their study participants thrice weekly to provide more in-depth one-on-one attention and feedback. Phone calls also were better suited for participants with confidentiality concerns and those who had difficulty traveling to the clinic or had scheduling conflicts with the set meeting times. An evaluation of the intervention is summarized elsewhere (Simoni et al., 2005).

Participants

Two peer training sessions were conducted over the course of the 3-year study. Six peers were trained during the original training session in 1999, and an additional six were trained in 2001. Peers remained actively involved for an average of 11 months (range: 9 months to 3 years). Specifically, one peer remained in Project HAART over the three years of the project, two left the project because they were no longer receiving services through the clinic, two left to pursue employment, two left because they felt they needed a change, four from the last training remained until the project ended, and one expired.

Peers were contacted for participation in the current study four months after the conclusion of the project. Ten of the 12 peers were invited to take part in an interview to discuss their experience as a peer (one peer was lost to follow-up and one had expired). Nine agreed to be interviewed; the one declining said she did not have time available.

These nine HIV-positive individuals trained as peers ranged in age from 41 to 62 years *(M =* 48). Five were female, and two described themselves as gay. The peers' ethnicity was representative of the population served at the clinic: six described themselves as African American, two as Latino, and one as White. Peers were diagnosed with HIV from 7 to 17 years earlier. Four peers reported previously abusing substances, one reported continued abuse of alcohol, and four denied previous and current substance use.

Data Collection Procedures

A project staff member who had limited contact with the peers prior to the interview process conducted in-depth individual interviews with them. During the interviews, peers were questioned about their relationships with their assigned patients and the experience of being a peer and invited to speak freely. The questions (e.g., "Can you describe the project?" and "How would you describe what you did as a peer?") were open-ended, promoting an environment conducive to sharing personal experiences. Interviews, ranging from 45 to 90 minutes, were audio-taped, and transcribed verbatim. Field notes also were taken to supplement the interview materials.

Additionally, seven peers participated in a focus group. The principal investigator and a project interviewer who had an established relationship with the peers conducted the focus group. The focus group allowed for further investigation of the peers' experiences, their relationships with peers, and other responsibilities. As in the individual interviews, the questions (e.g., "Can you tell me about your contact with the peers?") were open-ended, promoting an environment conducive to sharing personal experiences. As the peers had an established relationship with one another from previous support groups and peer supervisions, their group interview allowed for the emergence of information not available from individual interviews. As with the interviews, field notes were taken and the session was audiotaped and transcribed verbatim.

Data Analysis

Data for analysis consisted of the transcriptions from the individual in-depth interviews and the focus group. Data analysis followed the grounded theory approach developed by Auerbach and Silverstein (2003). This approach establishes three levels of data analysis. Three members of the research team read the text of the individual in-depth interviews and the focus group. Working independently, each researcher identified Relevant Text in the transcripts, and organized the Relevant Text into Repeating Ideas, and the Repeating Ideas into Themes.

The research group then met together to compare and contrast each other's organization of the data. After an extensive discussion, a final list of Themes was established, and these were grouped into Theoretical Constructs, which link the data to broader psychological theory. The Theoretical Constructs were then used to create a Theoretical Narrative that tells the story of this group of participants' subjective experiences of being peers providing social support to clinical patients who are HIV positive.

RESULTS

Table 1 presents the Repeating Ideas, Themes, and Theoretical Constructs that emerged from the data analysis. In the following section, we present the Theoretical Narrative that was constructed from the data. Initial of names are used to ensure participants' confidentiality.

Theoretical Narrative

I. Social Acceptance—Peers told a story that began with a description of the social isolation associated with having a diagnosis of HIV. "Sometimes having HIV makes you feel like you are the only one in the world." They stressed that one of the most important aspects of being part of the project was that it decreased this sense of isolation. The project gave the peers the opportunity to meet people who were experiencing some of the same things they were. "I heard everyone was going through what I was going through and people felt the same way I did." By meeting others who were experiencing the same things, they felt less alone and less stigmatized. "I know for sure I am not alone now."

Another advantage of the program was that the peers felt the group was a safe place to talk about painful topics. They felt their privacy and confidentiality were protected. "Whatever

you said in the room stayed in that room." "Everyone was honest and I knew no one would say anything about anything once we left the room."

II. Reciprocal Support—The peers got personal satisfaction from receiving and providing support. Peers gave support by "helping someone else who needs the help" and ". . . doing something for other people." Peers then obtained support in return. "I found that they (the participants) were there to listen to me" . . . . "he (the assigned participant) cared enough about me to keep calling." "We helped each other." Peers also reported receiving information. "I learned a lot of things I really didn't know about HIV in itself." "I learned how to ask questions or how to talk to the doctors" and "I learned about side effects."

The peers described receiving support on many different levels: social, emotional, informational, and spiritual. "You found something here they couldn't find no place else." In terms of emotional support, the peers commented: "Verbally we were able to talk about things they couldn't tell other people be it their husbands, moms, pops, or children."

III. Personal Growth and Empowerment—Peers reported that their participation and the information they received enabled them to feel more empowered with their own doctors. "Most people don't ask questions. I don't know whether we feel intimidated or we feel we are not going to know what they are talking about. The program made me feel like that is not true."

The peers talked about how much they had grown through their participation in the project. They were clearer about their capabilities. "Basically seeing what I was capable of doing to see what I could do and what I can't." "It gave me more insight into who I am. I gained an understanding that I don't have all the answers that I am still searching." They felt connected to others in their struggle against the disease. "We developed together. He (the participant) was willing to make changes."

They felt more confident. "It gave me more confidence to look into more things because of the positive experience." They felt a sense of satisfaction in helping others. "I really felt like I made a difference." This experience of altruism provided a sense of personal empowerment. "Through this strength I began to realize I was entitled to talk about the disease. I found that now I can talk freely to more people about the disease." This sense of empowerment and personal strength changed their sense of themselves, and their outlook for the future. "I am a totally different person now." "You see that your issues weren't that bad after all."

IV. Resistance and Other Challenges—Participation also was frustrating sometimes. Peers described some people who "just didn't want the help." "They were just in denial and nothing you can say is going to change that." Other people were "keeping a secret she wasn't willing to talk about it." They realized that there are certain people you cannot help. "There was times when you could help certain people and certain people you can't help."

Another difficult aspect of the program, one that is common in dealing with groups of HIV-positive individuals, is dealing with the death of a group member. The peers talked about

how difficult it was when someone died. "It is devastating. Getting close to somebody and then they are not there anymore." They did not feel prepared for the loss. "It knocked me for a loop because it didn't enter my mind like I said that I would lose somebody." The end of the project was also difficult for the peers, often in ways they could not fully articulate. "When they ended the project, I felt it was sad."

DISCUSSION

The benefits of social support to individuals with chronic illness, especially with a stigmatized illness, have been documented in the literature (Rudy et al., 2001; Mizuno, Purcell, Dawson-Rose, Parsons, & SUDIS team, 2003; Burrage & Demi, 2003). Research supports that an HIV-positive status is associated with decreases in social contact and support as well as increased feelings of social isolation than HIV-negative individuals (Schroeder et al., 2001; Kalichman, 1995).

Previous research in group therapy reported that one of the most important aspects about a group is that it allows participants to learn that they are not alone with their diagnosis (Bower, Kemeny, & Fawzy, 1999). Being with others who share a common experience fosters a sense of social acceptance and reduces the stigma associated with HIV. Research among groups with chronic illness similarly supported the finding that the key aspect of this type of support is the bond of common experience (Rogers, Bauman & Metzer, 1985; Dunn et al., 1999).

However, limited research has been conducted on reciprocal social support among HIV-positive individuals. Hays, Chauncy, and Tobey (1990) found that for most individuals with HIV, the opportunity to reciprocate support (as opposed to constantly being dependent) promoted greater psychological well-being. This also was found in other groups where effective support was most likely to come from others who were socially similar or facing the same stressors (Rudy et al., 2001). Schmitz and Crystal (2000) suggested that the psychological construct of *mattering* or *having a role* explained the relationship among social support, empowerment, and adjustment in HIV-positive individuals. The findings of the current study confirm these reports.

Research has found that informational support directly related to HIV as well as practical assistance with everyday needs helped improve coping with HIV infection (Belkin et al., 1992; Namir et al., 1990). In the current study, peers reported that receiving information about HIV, medication, and community services from other peers lessened their own fears and uncertainties.

Peers also described that over the course of their participation they began feeling comfortable enough to talk about religion and using it as a form of support. Research has confirmed that a spiritual perspective in a group of HIV-positive individuals was associated with successful coping with the stressors associated with an HIV diagnosis (Gray & Cason, 2002; Matthews et al., 1998).

The peers also reported that through their role as helpers, they began to feel more personally empowered. They felt more comfortable talking about their disease, and experienced a

change in outlook. Previous research has found that, when they feel empowered, HIV-positive individuals have been found to be highly interactive with their health care provider, involved in treatment decisions, and active knowledge seekers (Marelich et al., 2002).

Peers in the current study also described a change in outlook in relation to themselves, their environment and HIV. This aspect of growth has been supported by Rutter's theory of social support (1987), which reported that self-esteem arose from success in accomplishing tasks and helping others.

These aspects of developing personal growth and empowerment were not specifically evaluated in previous HIV peer interventions. This may be due to the fact that previous peer research primarily focused on peers who were non-HIV-positive volunteers. In peer programs that focused on peers diagnosed with other medical illnesses, including, heart disease and cancer, the peers were not evaluated on personal strengths or change in outlook (Whittemore et al., 2000; Dunn et al., 1999). This was due to the fact that the peers in these studies were in remission at the time of providing support. The peers in the current study were unique in that they were HIV-positive, of low socioeconomic status, belonged to minority racial groups, and for many had a history of substance abuse and unemployment.

In contrast to the positive aspects of providing and receiving support, peers reported encountering resistance and other challenges during their participation. This has been reported in research investigating burnout among peers (Maslanka, 1996; Claxton et al., 1998; Christensen et al., 1999). Maslanka (1996) reported that burnout arose from the stress of working with a high-demand population, emotional exhaustion, and lack of personal accomplishment.

The peers in the current study also spoke about the challenge of group members' dying. Difficulty with loss is documented throughout the peer support literature. In some cases, peers and volunteers have not been able to cope with an experienced loss and have disbanded as a result of death (Christensen et al., 1999; Schrimshaw & Siegel, 2003).

This was also evident with some of the peers in the project. Following the death of one of their fellow peers, two peers decided to leave the project to pursue outside interests and employment. When asked to describe the loss, the peers reported the difficulties they experienced by the unexpected death of a group member. In addition to the loss of a group member, peers experienced the loss of the program. Peers described this loss as out of their control.

In summary, the findings of the current study replicate many of the findings of prior research on peer support. However, the findings expand earlier research in terms of the uniqueness of the sample, i.e., peers who were HIV-positive themselves and from a highly marginalized population. Our findings illustrate that marginalized individuals without high levels of education can provide social support to others and benefit from performing that helping role.

LIMITATIONS

The current sample may not be representative of HIV-positive populations as it was limited to participants from an urban clinic in the Bronx, New York. Also, peers received payment for their services, and this payment, rather than the intervention itself, may have affected their initial interest and level of participation. The study also suffered from the limitations of all self-report studies in that the peers' responses may have been influenced by social desirability. Finally, it is difficult to know how the focus group format influenced the results. On the one hand, group discussion often stimulates participants to discuss issues that they might hesitate to mention in a one-on-one interview, especially if the interviewer is from a different class or racial/ethnic group. On the other hand, a group format can stifle discussion if participants feel pressure to conform to the attitudes expressed by other group members.

SUGGESTIONS FOR FURTHER RESEARCH

The study provides novel data on the experience of HIV-positive peers providing social support to other HIV-positive individuals. Being a peer provided an experience of reciprocal support and the opportunity for personal growth and empowerment. These positive findings suggest that this type of peer social support may be helpful adjunct to medical treatment of HIV-positive individuals. This kind of intervention might be especially beneficial in areas where there are scarce resources to provide assistance to patients. The findings should be replicated with larger and more diverse samples, which might examine additional benefits such as improved medication adherence, increased contact with the clinic, and superior health outcomes (perhaps via record review).

Future research might use the Repeating Ideas, Themes, and Theoretical Constructs that emerged in this study to develop a quantitative instrument to capture peer reactions to their experience. In addition, the peer model and intervention may be useful in other clinics, where it can be combined with ongoing programs for patients with HIV/AIDS or other chronic illnesses (those interested can contact the second author for additional information and a copy of the training manual). Future implementations might expand the scope of training, including more discussion of the potential for the loss of members through death, burn-out, or dropout. Tailoring the training, targeting a particular stage of illness, and perhaps expanding beyond the goal of enhancing adherence may result in a peer support intervention that is more widely applicable and perhaps more beneficial to both peers and those they aim to support.

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TABLE 1

Theoretical Constructions, *Themes*, and Repeating Ideas (*N* = 9)

I. Social Acceptance	
A. *Being with those who are going through the same thing*	89%
1. I heard everyone was going through what I was going through and people felt the same way I did (D.S.)	
B. *Feeling accepted within an otherwise isolating disease*	56%
2. I know for sure I am not alone now (C.B.)	
C. *Feeling safe in the program*	67%
3. Whatever you said in that room stayed in that room (D.F.)	
II. Reciprocal Support	
A. *Support from peers*	78%
4. You found something here they could not find no place else (J.S.)	
B. *Receiving support on many levels*	89%
5. Verbally we were able to talk about things they could not tell other people be it their husbands, moms, pops or children (A.F.)	
C. *By helping other people i got something in return*	100%
6. I found that they were there to listen to me. We helped each other (F.Q.)	
D. *Helping other people through example*	89%
7. I was doing something for other people (J.P.)	
III. Personal Growth and Empowerment	
A. *Feeling entitled enough to talk about disease*	67%
8. Most people do not ask questions. I do not know whether we feel intimidated or we feel we are not going to know what they are talking about. The program made me feel like that is not true (D.F.)	
B. *Being part of project HARRT gave me strength*	67%
9. It gave me confidence to look into more things because of the positive experience (#5)	
C. *Change in outlook*	78%
10. I am a totally different person now (T.S.)	
IV. Resistance and Other Challenges	
A. *Obstacles to accepting support*	100%
11. Certain people were just in denial and nothing you can say is going to change that (V.M.)	
B. *Certain people you cannot help*	56%
12. There was times when you could help certain people and certain people you cannot help (J.S.)	
C. *No control over loss*	56%
13. It knocked me for a loop because it did not enter my mind like I said that I would lose somebody (D.F.)	