“Positive Examples”: A Bottom-Up Approach to Identifying Best Practices in HIV Care and Treatment Based on the Experiences of Peer Educators

Marcia Veronika Dutcher, M.A.,1 Sheila Noely Phicil, M.P.H.,2 Sarah B. Goldenkranz, M.P.H.,3 Serena Rajabiun, M.A., M.P.H.,2 Julie Franks, Ph.D.,4 Brenda S. Loscher, Ph.D.,5 and Natabhona Marianne Mabachi, Ph.D.6

Abstract

Literature describing the roles and activities of peers working in HIV care is limited. Evaluations of the impact of peer-based behavior-change interventions reveal mixed results, due in part to varied program aims, structure, evaluation mechanisms, and training. Peers themselves are important resources to address these concerns and lay the groundwork for developing improved programs and evaluation strategies. This qualitative article describes peer support in HIV care and treatment from the perspective of 23 HIV-positive peers across the United States. Peers reported that peer characteristics (HIV-status, common experiences, and self-care) enable them to engage clients. Peers also required flexibility to respond to client needs, and their activities spanned four types of social support: informational, emotional, instrumental, and affiliational. We recommend peer programs and evaluations accommodate the broad scope of peer work by acknowledging the need for flexibility and activities that are not always directly related to clients’ HIV care and treatment.

Introduction

For over 30 years, a growing body of literature has described and systematically assessed the effectiveness of community-based peer services in assisting people with a variety of health needs. Evidence suggests that peers can positively impact patient access to care services, social support, involvement in self-care activities and self-efficacy. Peers may also contribute to cost effectiveness. However, a recent meta-analysis of the impact of peer-based interventions on changing health-related behaviors in adults concluded that results have been mixed.1 Diverse results of experimental peer interventions are challenging to interpret, in part because most published reports do not include a full description of peer activities’ reach and dose.2 In addition, a full description of the skills and qualifications of peers would improve understanding among funders, peers, and other project workers regarding the specific roles of peers as part of care and treatment programs.3 Recent articles describing in detail the implementation of peer interventions to support HIV services represent an important advance toward understanding the factors that contribute to the effectiveness of peer-based support for health care.4–7

An important and underutilized resource to address peer activities and identify consistent evaluation criteria is the collection of experienced peers currently working in the field of HIV care and treatment across the United States. A logical “bottom-up” approach, in which experienced peers describe the roles, activities, strategies, and elements they identify as important to their success, will help to better define peer roles. This approach may also be the first step in identifying best practices on which to model programs and structure evaluations. Although peer-based interventions vary, the underlying rationale for using peers is that peers share common characteristics with the target community8 that enable them to offer support, encouragement, hope and mentorship to clients.9 The

1St. Louis Area Chapter American Red Cross, Health and Safety Services, St. Louis, Missouri.
2Boston University School of Public Health, Health and Disability Working Group, Boston, Massachusetts.
3Center for Health Training, Seattle, Washington.
4ICAP Mailman School of Public Health, Columbia University, New York, New York.
5Kansas City Free Health Clinic, Kansas City, Missouri.
6University of Kansas Medical Center, Department of Family Medicine, Kansas City, Kansas.
role of peers has been generally described as an accessory to professional health and social services to providing support to vulnerable and marginalized populations.10,11

Although some studies show promise in their evaluation design,4,5 most studies examining the efficacy of peer-based interventions do not include detailed descriptions of how interventions are delivered in the experimental setting.5 If useful peer interventions are to be replicated, the processes through which peer services are delivered must be documented and analyzed.5,12 Qualitative research methods are appropriate for inquiry into the nature of peer services and the extent to which services are delivered according to programmatic definitions and expectations of peer roles.13,14 To our knowledge, literature describing the qualitative data that illustrates in detail the roles and activities of peers working in HIV care and treatment is limited.6,15

One of the fundamental roles for peers working in HIV services is providing support.16 In contrast to the limited literature and mixed results of peer-based interventions, a robust body of literature characterizes the nature of social support and clearly demonstrates its positive impact on chronic disease management.17 Social networks and social relationships have been found to be influential in maintaining health and bolstering individuals’ ability to fight illness among those living with a chronic illness, including HIV.18–21 Research has shown a positive impact of social support on people living with HIV/AIDS in terms of medication adherence;20,22–25 morbidity,26 safe sex practices,27 mental health,20,28,29 and disclosure of one’s HIV status.30

The literature on social support and HIV has primarily been limited to descriptive studies based on clients’ reports of the amount of support they receive from family, and faith-based and other community members.31 Throughout this literature a solid framework has been developed and utilized to characterize attributes of social support,25,32–36 and has also been used to explore the mechanisms through which it positively impacts HIV-related health outcomes such as medication adherence.25,37–38 Few studies have described interventions to increase social support to people living with HIV. However, in a review of peer-based interventions, Dennis39 explored provisions of social support and found that the same attributes of social support were common across a variety of programs with varied aims, settings, and structures. Similarly for this analysis we adopted the social support framework as a tool to describe the breadth of roles and activities of the peers in our study.

Social support has generally been divided into four categories. These categorizations are based upon the functional content within the studied relationship. The literature has inconsistently included a fifth category, appraisal support, as separate from emotional support. For the purposes of this study we focused on the four categories most consistently described in the literature: instrumental, informational, emotional, and affiliational support.33 Instrumental support is the “provision of tangible aid and services that directly assist a person in need.”22,40 Informational support is characterized by communicating advice or information to assist the person in addressing problems or conducting self-assessment.32,34 Emotional support is the “provision of empathy, love, caring and trust.”25,32 Finally, affiliational support conveys information that the person is part of a social network of reciprocal help or mutual obligation.36,33

This article utilizes qualitative data to explore in depth the roles and activities of peers working in HIV care and treatment, in the context of social support. Our purpose is to examine from the perspective of peers the factors and activities that influence peer success with clients. This “bottom-up” approach to identify what peers actually do to serve their clients will provide additional insight that can be utilized to evaluate new and existing peer programs. Furthermore, a detailed description of how peers help clients engage in HIV care will be useful for program planners, policy makers, and funders interested in integrating peers into HIV service delivery programs.

Methods

Sampling procedures

In 2005, the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau, Division of Training and Technical Assistance funded three sites and a multisite evaluation center to support HIV peer education efforts across the United States through the Peer Education and Training Sites/Resource and Evaluation Center (PETS/REC) initiative. The initiative was supported through HRSA with Minority AIDS Initiative (MAI) funding and was developed in response to the growing HIV epidemic in communities of color as a strategy to improve health outcomes and reduce health disparities in underserved minority communities. To achieve this goal, the initiative focused on two main activities: (1) training people living with HIV to serve as peers to engage other people living with HIV/AIDS in care and treatment and (2) building the capacity of organizations and communities to integrate peers into HIV care and treatment services.41 As part of a cross-site evaluation of activities, the three sites conducted a qualitative study of peers who completed training at one of the funded sites, self-identified as HIV positive, and who were working or volunteering in HIV/AIDS services. Purposeful selection techniques were used to select participants based on gender, race/ethnicity, and geographic location to reflect peers who were new to providing peer services (working with clients at least one month with no more than five contact with each client) and those who were more experienced (with more than one client and having had at least six client contacts since completing training) and peers not associated with an organization but doing advocacy in the community. An effort was made to select a group of diverse peers from within the participating sites to ensure perspectives of peers from both genders, working in rural and urban settings in diverse geographic locations across the United States. All sites and the multisite evaluation center obtained approval for the study from their respective Institutional Review Boards.

Data collection procedures

Two sites conducted eight in-depth interviews and one site conducted seven in-depth interviews, each using a semistructured guide that focused on describing two areas: (1) the peer’s role in his/her community, program or agency and (2) how peers believe their interaction with clients affects clients’ HIV knowledge, access to health care, utilization of services, adherence to treatment, and provider relationships, and other impacts of peer services on clients.
Interviews were conducted between June and December 2008, 3–15 months after peers completed the training program.

Data management and analysis

All interviews were audio recorded and transcribed verbatim. NVivo version 8 software (QSR International, Cambridge, MA) was used to code and analyze narrative transcripts. A team of researchers from the local study sites and multisite center developed a preliminary coding scheme from the interview guide that asked peers to describe their approach to working with clients, the nature of peer-client relationships, and what they perceived to be the impact and the value of the services they provided. Two researchers independently read and coded each interview. The team met to compare use of codes and resolve discrepancies in order to achieve consensus for fidelity and strength of coded passages. The data were then analyzed through a process of thematic content analysis. The researchers examined the coded passages and categorized them by activity-related subthemes, according to what activities peers reported and their perception of the effect of these activities on clients’ HIV care and treatment. Passages were selected that represented client needs and peer activities that fell within each category. Activities were included if reported by three or more participants. Each theme was then assigned to one or more of the four social support categories, as determined by consensus of three researchers.

Results

Description of peer educators

Table 1 shows the characteristics of the peer educators who were interviewed. The 23 HIV-positive interviewees were from urban and rural regions of the United States and represented a variety of demographic characteristics and peer-work experience. Sixty-five percent were female; most (78%) were African American; nearly a third (32%) had obtained a college or graduate degree; and 73% were heterosexual. The majority (78%) of the interviewees worked in a clinic setting while 35% had been working as a peer for at least 2 years, and 48% held paid peer positions. The median number of clients per peer was 15.

Context of peer–client relationship

To understand the context in which peers provide support to their clients, peers were asked questions about the type of relationship they had with their clients and how they engaged clients in HIV care and treatment. We observed several factors that formed the basis of the relationship, including mutually identifying as HIV-positive, having shared experiences, and role modeling.

HIV status was the primary factor that peers cited as enabling them to connect with their clients. Peers related to clients through the personal experience of living with HIV, including accessing health care, taking medications, participating in support groups, using community resources, and in some cases struggling with substance use. Peers reported that disclosing shared experiences to clients allowed them to establish credibility and motivate clients to change health behaviors.

### Table 1. Demographic and Work Characteristic

<table>
<thead>
<tr>
<th>Demographic and work characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>65%</td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
<td>35%</td>
</tr>
<tr>
<td>Average age&lt;sup&gt;a&lt;/sup&gt;</td>
<td>45</td>
<td>years (range 28–59 years)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American/Black</td>
<td>18</td>
<td>78%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>White</td>
<td>4</td>
<td>18%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College or graduate degree</td>
<td>7</td>
<td>32%</td>
</tr>
<tr>
<td>Some college or postsecondary</td>
<td>7</td>
<td>32%</td>
</tr>
<tr>
<td>Completed high school or GED</td>
<td>7</td>
<td>32%</td>
</tr>
<tr>
<td>Less than high school</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Region of residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midwest</td>
<td>8</td>
<td>35%</td>
</tr>
<tr>
<td>Northeast</td>
<td>7</td>
<td>30%</td>
</tr>
<tr>
<td>South</td>
<td>8</td>
<td>35%</td>
</tr>
<tr>
<td>Median year of HIV diagnosis</td>
<td>1995</td>
<td></td>
</tr>
<tr>
<td>Peer work setting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinic</td>
<td>18</td>
<td>78%</td>
</tr>
<tr>
<td>Community-based organization</td>
<td>3</td>
<td>13%</td>
</tr>
<tr>
<td>AIDS service organization</td>
<td>2</td>
<td>9%</td>
</tr>
<tr>
<td>Peer work status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid</td>
<td>11</td>
<td>48%</td>
</tr>
<tr>
<td>Volunteer</td>
<td>12</td>
<td>52%</td>
</tr>
<tr>
<td>Length of time as a peer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>4</td>
<td>17%</td>
</tr>
<tr>
<td>6 months to 2 years</td>
<td>8</td>
<td>35%</td>
</tr>
<tr>
<td>More than 2 years</td>
<td>11</td>
<td>48%</td>
</tr>
<tr>
<td>Median number of clients</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Total number of interviewed peers</td>
<td>23</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup>Dates ranged from 1985 to 2006.

Some peers saw themselves as positive examples for their clients (and others with HIV) of the rewards of good self-care. Peers described themselves as role models. Peers did not directly model healthy behaviors such as keeping medical appointments, in front of their clients; instead they saw themselves as “living proof” of the “reward of doing things correctly.” This was coupled with a recognition on the part of peers that it is important to “practice what I preach” in order to be an effective role model.

Peer activities in the context of social support

Beyond describing the context of their relationships with clients, peers described how they assessed and responded to the needs of their clients. They identified a broad range of urgent needs facing their clients and defined their scope of work around those needs (Table 2). Peers targeted issues directly and indirectly related to HIV care and treatment based on their assessment of clients’ needs. They often intentionally steered conversations with their clients toward discussion of
client’s health behaviors, explicitly critiquing negative behaviors and recommending alternatives, as well as reaffirming positive behaviors.

When asked more specifically about what they do to help their clients, peers’ self-defined scope of work included activities directly related to clients’ HIV care and treatment and responding to additional needs, such as housing and food. Peers’ descriptions of their activities spanned all four of the social support categories considered (informational, emotional, instrumental, and affiliational). Certain client needs could be addressed by just one area of social support while more complex behavioral issues such as medical adherence were often addressed by a mix of more than one social support method. Table 3 shows a comprehensive list of the activities peers described, classified according to the relevant social support category.

**Instrumental support** Peers performed many instrumental support activities to directly connect clients to HIV care and treatment resources such as referring clients to providers, helping clients research health information, scheduling appointments, making calls to remind clients of appointments, and transporting clients to/from appointments. One peer stated, “If they [client] want to research some medications they are taking I’ll do what I can to get them to the food bank.” Another common type of instrumental support was making referrals for clients. As one peer explained, “I had this lady, I had never met her before, she called into [organization]. She was newly diagnosed and she needed to know where could she go to get care…I contacted [the] doctor and gave her information and she got her into care…the same time she was looking for care, she has kids and her lights was getting ready to get cut off, and I got her to an agency that could help her pay her light bill.”

**Informational support** Peers described themselves as advocates who help clients learn and understand HIV-related medical information. This involves educating clients about a variety of topics, as well as helping clients better comprehend medical information from his/her health care providers. Peers did not view themselves as replacements for the provider, rather as someone who could clarify the information by presenting it from a layperson’s perspective. One peer explained how she assisted a young lady whom she was working with for about a month, “The doctor is wanting her to start on treatments and she wasn’t ready. But after I talked to her…I just broke it down on how the medications work…she understood so at her next appointment she told the doctors, ‘I’m ready. I’m ready to…start medications.’”

The most frequent informational support activity was helping clients to understand the importance of treatment adherence. A peer stated, “I think our position as peer educators is very pivotal in helping people to understand the importance of taking their medicines because so many patients think that they look good and they feel good so they don’t have to take medicines…” Although less common, peers also described educating clients about other health topics indirectly related to HIV care and treatment. For example, a peer said, “I have been teaching people about nutrition and food—what foods are healthy, what foods are good for us, and about exercise and how important it is for our way of life, quality of life.”

Another major type of informational support was helping clients to navigate an unfamiliar health care system. Working in conjunction with the formal health care system, peers helped clients who were new to the system by counseling them on what to expect. These activities were not limited to guiding clients through the facility, but also helping familiarize and prepare clients for the medical procedures they will experience. A peer stated, “I educate people that are newly diagnosed or just starting meds for the first time. My job is to navigate them through the system so they know about their disease, [and] what to expect when they start taking meds.”

Peers helped clients prepare for their medical or lab visit by coaching them on how to advocate for themselves. A peer explained, “I inform them on…what questions to ask, what to look for, how to understand their labs, why they’re drawing blood.” Peers also noted that clients often do not understand their lab readings, even when a provider has previously explained them; hence the peers support clients by reviewing and clarifying the information. A peer educator stated, “I told [the client] last week when I met with him that I would be at his appointment so when he’s finished with the doctor and the nurse that I would like to review everything and where his numbers are…and be there for him.”

**Emotional support** The peers in our study described the importance of providing emotional support, something they
observed most clients lacked. Peers described their clients as emotionally isolated, and stressed the importance of taking time to demonstrate caring, empathy, and comfort to help clients begin to engage in HIV care and treatment. For example, several peers noted that clients just needed someone to take the time to listen to them, to alleviate their fears. One peer shared, “A lot of times they want someone to listen to them. So I will just sit there and…every once in awhile interject a thought or an idea, but if a person is very emotional and wants to cry, which I think is very therapeutic, I let them do that.”

Peers used listening and reflective techniques as a means to help clients gain confidence in their ability to change health-related behaviors. A peer explained, “By me sharing my story [and] by me spending the time to listen [to] what’s going on with her….it gave her great impact on her life to want to get it back together.” Another peer reflected when clients share details about their lives, a peer can use these details as an entry point to directly discuss HIV care and treatment, “Now I see where I do the most help is by…listening to what’s going on in their lives and then I incorporate….Is this affecting the way you take your medicines? Is this rough relationship you have at home keeping you from staying clean and sober?”

Peers intentionally appealed to their clients’ emotions in order to reinforce or change behaviors. This was often done using words of encouragement and advice. As one peer put it, “We….verbally tell them that we care about them.” A peer described how she appealed to the clients’ self-image as a way to reinforce good behavior, “When you see that they’re well-groomed that day…” by acknowledging it aloud, the client thinks “Somebody noticed that I’m doing the right thing, and it makes me want to do the right thing some more.”

Another peer described brief interactions with clients in which he integrated emotional and informational support, “If they give me 5 minutes to sit down, then we will talk about the health issues…Then we may….do a little exposure and disclosure issues.” Then the peer adds a directive, “Some of them talk about how they are not satisfied with their treatment…and I tell them ‘Well you have got a choice’.”

**Affiliational support** In addition to emotional support, peers provided affiliational support to help draw clients out of isolation. The peers frequently spoke about initiating social connections for their clients to help them create an environment that enhanced and supported their health and wellness. This was predominantly carried out in social gatherings where clients had opportunities to bond with one another and build a social network. A peer described, “We go out for a group activity, and that helps a lot of people because there’s a group of us….who have taken the courage to get out together.” Another peer encouraged the building of social networks among clients by introducing a cooking program during workshops where in place of ordering food, the peer and clients cook together, “We get closer like that through sharing the food.”

In addition to social activities designed to reduce isolation and help clients connect to social networks, peers integrated opportunities for clients to become more informed and engaged in their HIV care and treatment. Some activities were
planned as social and educational opportunities. One peer explained, "We have health fairs, we go on trips to the mountains, to the beach, conferences that are more like a learning experience." Another peer described how engaging in these activities has improved her clients' self-care behaviors, "We have 'Lunch and Learns' and dinners with different speakers that talk about different opportunistic infections...I do everything I can to get my patients to go to those things and to be involved and about a third of them have become involved...and the ones that are more active are the ones that are more adherent."

Discussion

Our results show that peers have a unique ability to engage and motivate clients because they can relate to them, have experienced similar challenges and serve as HIV-positive role models who live a healthy, balanced life. Peers view their role broadly, and perform a wide variety of activities based on their own assessment of each client's needs. All peers described activities that involved directly educating and connecting clients to health care resources. However, many also described additional activities falling outside the realm of care and treatment support that respond to clients' basic needs and may play an important step in engaging clients in care and treatment. We found that peers provide all four types of social support. These findings have implications for how peer interventions can be structured and evaluated.

Our first finding was that identifying as HIV positive, having first-hand experience with the challenges of living with HIV and being willing to disclose this information to their clients were elements that peers identified as crucial to establishing a connection through which they could engage clients in HIV care and treatment. Several peer-based interventions have been able to foster strong peer relationships by intentionally selecting peers who shared similar characteristics and struggles with the target population such as HIV-positive status and drug use. Peers disclosed their HIV-positive status to clients because it helped establish a comfortable, credible, and mutual relationship. Peers shared stories about particular experiences they'd had as someone living with HIV because they found this helpful to clients to see themselves making health choices. Our findings are supported in the literature by Hilfinger who described how HIV-positive women gained entry into their clients' lives by telling their own stories and incorporating their own life experiences into their work. The unique nature of this relationship enabled peers to help clients adopt new healthy behaviors when, from their perspective other healthcare providers had been unsuccessful in doing so.

That peers build rapport with clients through shared experience living with HIV has implications for how agencies select individuals to serve as peers. In the process of selecting peers, it may be important for organizations to seek HIV-positive individuals who are comfortable disclosing their HIV status and personal experiences. It may also be important for agencies to select peers who have good self-care and can provide clients with a role model who demonstrates the feasibility of carrying out the self-care behaviors they advocate in daily life. Additionally, organizations that discourage peers from disclosing personal information to clients should recognize that peer-client relationships are built around bidirectional communication and disclosure, and that this differentiates peers from clients' other health care providers. Other research on this subject confirms that clients are generally more willing to talk to someone who "has been there." Another finding of our study was the extent to which the peer's role and activities were shaped by the needs of the client. The peers described how flexibility in their roles enabled them to provide a wide variety of client services, both directly and indirectly related to the clients' HIV care and treatment. Although in our analysis we separated activities as "directly" and "indirectly" related to clients' HIV care and treatment, peers themselves did not draw this distinction. When asked about the services they provide peers' responses flowed fluidly between a variety of medical and nonmedical services and they did not prioritize one above the other.

Working or volunteering in primarily clinical settings, the peers in our study spent substantial amounts of time dealing with clients' social, emotional, and physical needs beyond HIV care. Other research has stressed the importance of these types of peer support activities as they provide both buffering effects (protecting individuals from responding harmfully to potentially stressful events) and mediating effects (influencing an individual's self-efficacy) that positively impact health outcomes. Peers' openness to the variety of needs their clients expressed may reflect the nature of the peer-client relationship, in which peers and clients share backgrounds and life experiences, including the challenges (e.g., housing, food, security, substance abuse) that may interfere with regular access to health care. Capitalizing on the flexibility of peers to address clients' emotional, social, and practical needs may benefit programs aimed at retaining patients in HIV care, given that barriers to entry and retention in care have emotional as well as structural dimensions.

Despite potential benefit to clients, allowing flexibility may pose difficulties for the structure and evaluation of peer programs. Many HIV care organizations struggle with how to build the capacity of their programs to utilize peers. Peers can be valuable in complementing and enhancing the work of other providers as active participants in multidisciplinary team meetings. However, a number of the activities that peers perform in supporting their clients may overlap with the roles of other ancillary service staff, such as case managers and social workers.

Consequently, agencies that seek to utilize peers would benefit by clearly defining the role of peers with respect to how they fit into the overall goal of the agency in relation to the services or resources offered by other providers. Peers also need to be well-informed of the community and health service system infrastructure, so that they can provide referrals to existing resources rather than duplicating or overstepping the roles of other health care providers. Additionally, it may be important for funding agencies to acknowledge that peer-based interventions may be better suited to impact a broad range of factors, rather than a single specific outcome.

The peers' broad roles and range of day-to-day activities also help to explain why the design and evaluation of peer interventions of HIV care and treatment have varied substantially. The services peers provide are heavily tailored to each client's needs and often extend well beyond HIV-related medical services. Developing a common set of evaluation criteria for HIV peer support may not be realistic but evaluations of the impact of peer programs could take into account...
the range of services peers provide and the variety of both intermEDIary and long-term outcomes for different clients. Intermediary outcomes that ought to be evaluated include improved understanding of medical issues (the disease itself, medications, and lab values), attendance at clinic visits, and more active participation during clinic visits (asking questions, etc.); longer term outcomes include medication adherence and improved health status as indicated by laboratory tests such as CD4 and viral load.44 A further aim of evaluations should be to incorporate methods to assess how the additional services peers provide that extend beyond direct medical care (e.g., nutrition, housing security, engagement in social activities, etc.) impact clients’ engagement in HIV care and treatment as well as overall health.

A strength of this study is that the peers were recruited from many different peer programs that vary with respect to geographic location, agency type and mission, peers’ job titles, and employment status (paid versus volunteer). Despite these differences, we found that categorizing peers’ activities according to social support attributes (informational, instrumental, emotional, and affiliational support) provided a comprehensive and easy-to-use framework to characterize how peers working in HIV care support their clients. This corroborates Dennis’39 finding that the attributes of social support are relevant across a variety of peer interventions.

Although we found many clear examples of each type of social support, peers described addressing complicated issues such as medication adherence from multiple angles by integrating several types of support. For example, a peer could provide emotional support and informational support to a newly diagnosed client to help the client come to terms with the diagnosis and build the individual’s sense of confidence and responsibility for self-care. Upon building the client’s confidence, via emotional support, peers can help clients engage more actively in their own care and treatment through other support methods, such as accompanying them to doctors’ appointments (instrumental support) or encouraging them to attend events to be more informed about their status and connect with other individuals who are HIV-positive (affiliational support).

Effective peer programs in other disciplines have been shown to work in part because peers ‘have been there’ themselves and are personally familiar with the challenges their clients face.48,49 The peers in this study reported that the substantial amount of time they spend helping clients come out of isolation and develop a sense of self-efficacy is a critical factor in influencing clients’ self-care and healthcare-seeking behaviors. Though the benefits from these types of activities on clients’ engagement in their own HIV care may be difficult to measure, it does not imply that the benefits are nonexistent. In the field of social support, research has been done on the mechanisms through which social support from friends, family, and community has improved treatment adherence among HIV-positive individuals, and has shown that the individuals benefit because they learn to replace avoidance with better coping skills and positive states of mind.37,38 Further research is needed to explore the extent to which similar benefits occur when clients are paired with a peer as part of an HIV-care intervention.

There were a few limitations to this study. First, the peers selected to be interviewed were a relatively small purposeful sample of peers participating in the PETS Initiative. Their experiences may not be reflective of all peers participating in the initiative. However, care was taken to select peers who varied with respect to their demographic characteristics, geographic location, and length of time working as a peer.

Another limitation of this study is that the interviews were conducted by different interviewers, and although a common interview guide was used, interviewers varied in the extentiveness of follow-up questions they asked. This limited our ability to quantify the proportion of peers who reported having performed particular activities because we were unable to differentiate those who did not perform an activity from those who were not asked about it. However, this did not limit our ability to analyze and describe the breadth and depth of activities that peers described.

To the best of our knowledge, this article contributes to the emerging body of research examining the role, nature, and perceived impact of peer activities in HIV care, from the peer perspective. The findings from this study will be useful in building the capacity of HIV care organizations that want to use peers to improve HIV care and treatment, informing funding agencies of the utility and nature of peer programs, and develop program evaluations to examine the short-term, long-term, direct, and indirect impacts of peer services on clients’ HIV care and treatment. Future research should also solicit client perspectives on the support they receive from peers. Incorporating a perceived social support assessment would provide useful information to supplement other longer term outcome indicators such as health care utilization, treatment adherence, and CD4/viral load counts.

Acknowledgments

This research was supported by a cooperative agreement from the Health Resources and Services Administration through the HIV/AIDS Bureau’s Division of Training and Technical Assistance with Minority AIDS Initiative funding. The authors thank all the participants of this research project and the PETS staff: Shailey Merchant Klinedinst, Simone Phillips, Alicia Downes, Paul Colson, David Fine, and Edith Ablavsky.

Author Disclosure Statement

No competing financial interests exist.

References


Address correspondence to:
Marcia V. Dutcher, M.A.
3707 Jefferson Street
Kansas City, MO 64111
E-mail: marciadutcher@yahoo.com