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Embodied Work: Insider Perspectives on the Work of HIV/AIDS Peer Counselors

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Embodied Work: Insider Perspectives on the Work of HIV/AIDS Peer Counselors

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Our aim in this study was to explore HIV/AIDS peer counseling from the perspective of women actively engaged in this work within the context of a community-based program in rural areas of the southeastern United States. Based on this research we suggest that the embodied work of HIV/AIDS peer counselors is constructed around their personal identities and experiences. This work involves gaining entry to other HIV-positive women's lives, building relationships, drawing on personal experiences, facing issues of fear and stigma, tailoring peer counseling for diversity, balancing risks and benefits, and terminating relationships. Peer counselors recognize the

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personal and collective value of their work, which, like much of women's work within the context of family and community, lacks public visibility and acknowledgment. We discuss implications for the training and support of peer-based interventions for HIV and other women's health issues across diverse contexts and settings.

Peer-based interventions are well established in many public health and social service settings and are increasingly popular as a strategy for reaching disenfranchised and marginalized groups around the globe (Boudin et al., 1999; Eng, Parker, & Harlan, 1997; Everly, 2002). Despite the recent popularity and proliferation of peer interventions, there is a need for more in-depth and contextualized knowledge of this approach (Campbell & Mzaidume, 2001). In particular, there is a need to understand the processes of peer counseling and education (Wolf & Bond, 2002) in order to design programs that contribute to positive health outcomes among those receiving peer-delivered interventions and, at the same time, support the health and well-being of the peer interventionists. In this article we provide a brief overview of the literature on peer outreach and support interventions; describe the context of a peer counseling intervention program for HIV-positive (HIV+) women in the southeastern United States; and present the findings of our qualitative descriptive research on the experiences and perspectives of women engaged in HIV/AIDS peer counseling work.

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PEER INTERVENTIONS

Individuals engaged in peer interventions have been given diverse titles including peer counselors, lay health advisors, indigenous health care workers, cultural brokers, community outreach workers, and natural helpers. The peer approach is based on the assumption that individuals recruited from within a particular reference group will tend to have similar backgrounds and experiences that will enable them to access and provide support to other group members in more diverse settings and contexts (e.g., outside the formal health care system) and provide peers with credible, culturally appropriate information (Broadhead, Heckathorn, & Grund, 1995; Dickson-Gomez, Weeks, Martinez, & Convey, 2006). Another key assumption is that although peer helpers and recipient group members may be strangers at the onset of an intervention, group members will tend to accord peer helpers a level of trust and authenticity that cannot be achieved by professional caregivers (Hartman, Radin, & McConnell, 1992).

Natural helpers exist in most societies and are individuals to whom others turn for information, advice, emotional support, and tangible aid. In many communities across the globe, natural helpers serve as the primary contact with the formal health and social service system. Conceptually and

in practice, natural helpers are distinct from and do not take the place of professional providers (Service & Salber, 1999). Yet natural helpers interact with peers in a paraprofessional role that complements and extends the more specialized role of health professionals and the services offered by the health care and social service delivery systems. Empathy and nonjudgmental interest in helping others in similar situations allow peer counselors to develop trusting and supporting relationships that can facilitate desired client outcomes (Sherman, Sanders, & Yearde, 1998). Peer helpers serve as a bridge between the service delivery of formal agencies and institutions and the community's informal social support network (Centers for Disease Control and Prevention, 1996; U.S. Department of Health and Human Services, 2004). They also may augment the reach and relieve some of the pressure on existing services, therefore contributing to cost savings (Centers for Disease Control and Prevention, 1996; U.S. Department of Health and Human Services, 2004). In evaluating the affordability of peer interventions, however, it is necessary to acknowledge the costs of recruiting, training, and supporting peer interventionists (Elford, Sherr, Bolding, Serle, & Maguire, 2002).

Peer interventions have been used in a multitude of women's health programs and contexts across the globe, ranging from breastfeeding support for women in Bangladesh (Haider, Kabir, Huttly, & Ashworth, 2002) and Latinas in the United States (Chapman, Damio, & Perez-Escamilla, 2004; Chapman, Damio, Young, & Perez-Escamilla, 2005), to HIV/AIDS interventions in the Netherlands (Martijn et al., 2004), China (Molassiotis et al., 2002), Ghana (Wolf & Bond, 2002), and South Africa (Campbell & Mzaidume, 2001). Examples of the wide diversity of peer support programs in women's health include smoking cessation and recovery from substance abuse among pregnant and postpartum women (Malchodi et al., 2003; Sherman, Sanders, & Yearde, 1998; Woodruff, Talavera, & Elder, 2002); peer interventions targeting the husbands and fathers of women enrolled in nutrition support programs (Stremler & Lovera, 2004); and the promotion of physical activity to reduce the risk of cardiovascular disease and diabetes (Keyserling et al., 2002; Kim, Koniak-Griffin, Flaskerud, & Guarnero, 2004; Matson-Koffman, Brownstein, Neiner, & Greaney, 2005). In the mental health arena, peer support has been used for individuals with depression and psychological distress (Dennis, 2004; Molassiotis et al., 2002, Moneyham, 1999) and for persons with traumatic brain injury and their families (Hibbard et al., 2002).

Evidence is beginning to accrue that demonstrates the effectiveness of peer counseling in promoting positive health outcomes, particularly for vulnerable populations at high risk for health disparities. A peer counseling approach has been shown to be particularly effective in efforts to prevent the spread of HIV infection and to better manage HIV disease. In contrast to professional providers, peers are more likely to be successful in reaching HIV+ individuals in community settings. In comparing a traditional provider–client model with a peer-driven model to improve adherence to HIV treatment

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among injection drug users in the United States, Broadhead and colleagues (2002) noted the benefits of the latter, where peers provided guidance and played an active role in outreach processes. Their research indicated that peer educators had a more effective outreach role, when compared when traditional outreach workers, and that peer-driven interventions reached a larger and more diverse segment of the target population at a much lower cost. Another successful HIV peer intervention was the Risk Avoidance Partnership, in which active drug users were trained as peer health advocates to provide harm reduction materials and information in the community, both on their own time and partnered with professional staff (Dickson-Gomez, Weeks, Martinez, & Convey, 2006). The majority of the peer advocates were ethnic minorities (52% African American and 41% Hispanic) and 36% were female. The process evaluation of the Risk Avoidance Partnership program indicated that the peer health advocates conducted most of their outreach in public locations, in places where they intervened at critical moments when HIV risk behaviors were more likely to occur. Similarly, a London-based peer HIV and sexually transmitted disease prevention intervention was deemed successful in reaching the intended population of men having sex with men in a public sex environment and addressing their needs, in part because of the high levels of commitment and input from the peer volunteers (French, Power, & Mitchell, 2000).

Despite the growing evidence supporting the effectiveness of peer counseling interventions, little is known about the nature of peer counseling work, the mutual processes involved, and the effect of the work itself on peer counselors. Anecdotal evidence and findings from a few studies suggest a number of positive effects for peer counselors (Arnstein, Vidal, Wells-Federman, Morgan, & Caudill, 2002; Brunier, Graydon, Rothman, Sherman, & Liadsky, 2002; Paxton, 2002; Raine, 2003). The potential for negative effects also exists and should be explored. Furthermore, peer helpers have knowledge and insights about activities and processes that can enhance and advance models of peer interventions. Our aim in this research was to expand and enhance current understanding about the work of women engaged in peer counseling interventions among vulnerable groups, specifically HIV+ women living in rural areas.

BACKGROUND AND CONTEXT

The context for this qualitative research was the Rural Women's Health Project (RWHP), a larger longitudinal study (Messias, Moneyham, Murdaugh, & Philips, 2006; Moneyham, 1999) that tested the effects of a peer-counseling intervention on health outcomes of rural women with HIV disease in the southeastern United States. The RWHP peer-counseling intervention was developed in response to findings from prior research that indicated specific

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barriers and difficulties faced by rural women with HIV/AIDS. Because of HIV-related stigma and lack of transportation and supportive resources, rural women with HIV disease were not able or willing to obtain the support of other HIV-infected individuals (Moneyham et al., 1996). All components of the RWHP research were reviewed and approved by a university Institutional Review Board.

The RWHP peer counselors were recruited from 10 HIV/AIDS service organizations located in rural areas of three southeastern states. Staff members at these organizations were asked to identify HIV+ women who exhibited the characteristics of successful peer counselors, as described in the literature. These included the following: strong communication skills; ability to accept responsibility; good judgment; desire to help others; knowledge of available resources; skill in managing various aspects of their HIV disease; empathy and warmth; and ability to maintain confidentiality. Each organization was able to identify several women who demonstrated the desired characteristics. The RWHP staff interviewed and assessed potential candidates, using the following selection criteria: age 21 or older; a minimum of 3 years since diagnosis of HIV; possession of a valid driver's license and access to transportation; no physical or mental symptoms or limitations that would impair one's ability to implement the peer counselor role; a minimum of 5 years free of substance abuse; and willingness to make a long-term commitment to the project. The original intent was to include only candidates with the equivalent of a high school degree or higher level of education. Because several potential candidates had not completed high school, this criterion was dropped and preference was given to candidates who demonstrated skill in communicating both verbally and in writing, regardless of educational level.

The RWHP team provided an intensive training program to prepare the selected HIV+ women to implement the peer counseling intervention. Throughout the program, the peer counselors continued to receive ongoing support and training from the RWHP professional staff. The individual peer counseling intervention focused on issues and problems of greatest concern to women living with HIV. For the duration of the research project, peer counselors provided face-to-face peer counseling to individual women assigned to them. On average, each peer counselor was assigned 15 women for each 6-month period. Peer counselors met face to face with participants every 2 to 3 weeks to provide emotional and informational support. Following completion of each counseling session, the peer counselor met with a RWHP field supervisor to review the session and to plan the next encounter, including identification of strategies to address problems and concerns identified as the sources of women's psychological distress. A subset of participants received the same intervention via telephone (Messias et al., 2006).

The RWHP peer counselors assisted clients in accessing resources, services, and other HIV-related support networks that the women could turn

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to when the peer counseling relationship was terminated. Participants were prepared for eventual termination of the 6-month peer counseling relationship from the beginning and received frequent reminders of when the peer counseling support would end. Peer counselors and program participants were paid $20 for each completed counseling session.

METHODS

As part of the RWHP process evaluation, in the third year of the project we conducted a qualitative study of the experiences and perspectives of the HIV/AIDS peer counselors.

Participant Recruitment

A total of 24 women were trained as peer counselors for the RWHP over the 3-year study period. We invited eight peer counselors who were engaged as peer counselors during the final period of the project to take part in the qualitative study; six women agreed to participate. All six participants had provided peer counseling to rural women with HIV disease for approximately 2 years.

Once a RWHP peer counselor agreed to participate in this qualitative study, we scheduled an individual interview. The investigator who conducted the interviews had no prior contact with the peer counselors and was not involved in the training or supervision of the RWPH peer counselors. Informed consent was obtained prior to conducting the interviews. Face-to-face interviews were conducted at a university research center and at a community-based HIV/AIDS clinic. Due to distance and transportation issues, two interviews were conducted by phone. Upon completion of the interview, each participant received monetary compensation for her time and reimbursement for any travel expenses.

The audiotaped interviews lasted from 45 to 60 minutes. The interviewer followed a semistructured interview guide, designed to maintain the focus of the interview while allowing for the flexibility needed to respond appropriately to each participant's interview context and content. To elicit peer counselors' personal perspectives and experiences, the interviewer posed broad, open-ended questions, such as the following:

> Tell me about your job as a peer counselor.
> How did your personal experiences or previous work you have done help prepare you for the work of being a peer counselor?
> What were the most difficult parts about the job of peer counseling?
> What did you enjoy most about this job?
> How has being a peer counselor made a difference in your own life?

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Interpretation and Presentation of Data

We chose a feminist narrative approach for the data analysis, incorporating techniques drawn from constant comparative, thematic, and feminist narrative interpretative methods (Messias & DeJoseph, 2004; Riessman, 1993; Strauss & Corbin, 1998). Listening, coding, reflecting, and identifying themes and storylines were some of the key interpretive processes involved in the data analysis.

Listening involved interaction with the data at various levels and was an integral part of the interpretive process. Attentive listening occurred during the interviews with the women, but as previous experience with qualitative interviewing has shown, the listening that occurs during actual interviews tends to be selective (Messias & DeJoseph, 2004). Listening processes continued in other contexts, such as listening to the audiotapes and studying and analyzing the written transcripts. In a broad sense, the work of interpreting was another way of listening (Devault, 1990). The initial reading of each transcript also involved open-coding and identification of key words, in vivo codes, and themes (e.g., gaining entry, opening doors, dealing with stigma, steering them in the right direction). More focused coding and cross-participant reflective comparisons followed, leading to the development of the major storyline that evolved from the notion of "bringing myself to my work" into "peer counseling as embodied work." We continued and fine-tuned the analysis throughout the process of re-presenting the data and analysis in manuscript form.

The presentation of the findings includes substantial data from the interviews, woven together with our interpretations. To improve readability, we formatted the participants' words, originally spoken in the context of the research interview conversations, into sentences and paragraphs; introduced elements of structure (e.g., order of presentation, punctuation); and judiciously removed some repetitive aspects of oral speech (e.g., "um," "like," "you know"). In the presentation of the data, words inserted to provide clarification are enclosed in square brackets; omitted material is noted by ellipsis points; and verbal emphasis is denoted by italic type. To protect participant confidentiality, we removed or altered all identifying information.

FINDINGS

Participant Characteristics

The six peer counselors ranged in age from 29 to 51 years ($M = 41$ years). Four were African American and two were Caucasian. Four were single women who did not have dependent children living in the home. The two married women had young children living in the home. Two were high school graduates who also had completed some college; one had completed a General Educational Development test, which indicates high school

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equivalency; and the other three had less than a high school education. Prior to joining the RWHP, half were unemployed and the other half had part-time employment, primarily in low-paying jobs as unskilled workers. Among the single women, two reported an income level of less than U.S.$5,000 per year, one less than U.S.$10,000, and one less than U.S.$20,000. Among the married peer counselors, one woman's household income was less than U.S.$10,000 per year, and the other woman's income was greater than U.S.$30,000. The number of years since HIV diagnosis ranged from 5 to 15 years; four women had been diagnosed for more than 10 years.

The Embodied Work of HIV/AIDS Peer Counseling

Listening to the HIV/AIDS peer counselors describe their work resulted in a clearer understanding of the social constructions, meanings, and ways in which women embodied peer counseling work. The qualitative data illustrate how life and work were intertwined for these HIV/AIDS peer counselors. They incorporated their own life experiences into their work, serving as living examples for other HIV+ women. The embodied work of HIV/AIDS peer counselors involved telling their own stories to gain entry to other women's lives; "opening doors" to overcome fear and stigma; and steering women toward economic, social, and health resources. In assessing the impact of their work, the peer counselors recognized the challenges of tailoring their work to the specific needs of other HIV+ women. They acknowledged inherent personal risks and challenges as well as the mutual benefits to both counselors and recipients. In the following sections we provide our interpretations of these findings, illustrated through data excerpts and narratives.

Telling Stories: Gaining Entry and Building Relationships

The HIV/AIDS peer counselors identified relationship building as the essence of their work in helping other HIV+ women.

> That's what people need. Sometimes they need healing and it takes a relationship until they can learn to stand up. Until they can learn that, you help them to find that.

In order to build relationships, peer counselors first had to gain entry to other HIV+ women's lives. Telling one's own story was often an effective way to gain entry to other women's lives:

> I don't think I left one person's house that I didn't feel comfortable with the next time I went. . . . Usually what I would do when I went inside is, *I didn't* sit down and say, "Okay, tell me your story." So I went in and kind of told them *my* story. And so even if the first meeting was . . .

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> talking about me and my experiences and stuff like that, it was like an open door. The next time I would come and they were excited to see me.

Creating the space where other women could listen, and talk when they were ready, was an important part of gaining entry and developing a relationship:

> You call and you listen, and [ask], "How are you doing? Are you alright? Anything I can do for you?" Questions like that. Then let them ease themselves in it. If they don't say nothing, you just tell them about your experience dealing with it. Then they want to listen.

Gaining entry to another woman's life was not always easy. Navigating a new client's social context and environment could entail dealing adroitly with uncertainty, particularly in terms of ascertaining the extent of disclosure within a client's home or family environment:

> I had to ... be careful about [saying], "Well, I'm Bernice, I'm a peer counselor," because I don't know whether you told everybody in your family. I come to find out that a lot of them family don't even know. Don't know. Don't know that they on medication. Don't know that they're going to the doctor for that reason and living together every day. ... I went to [visit] one time this lady and her [male] friend did not know anything. And I showed up. She was expecting me, but she didn't expect him to be there at the time I was supposed to be coming; so I had to be careful about what I asked her. ... You're supposed to be confidential, you know. I was like, "Oh, goodness," and she's not saying too much and I don't know what to say. ... I'm just asking her, "How you doing" and couldn't talk about really what [I was there for], ... so when I got back home, I called her. I said, "Listen, we gonna have to do some serious talking, because I don't know how you're feeling and what you're doing, ... because when I came over we couldn't talk [with] your man sitting right there."

A shared identity as HIV+ women was the primary basis for the peer counseling relationship. One counselor aptly differentiated her role as a peer counselor from that of a professional:

> That's what peer counseling should be. ... Peer is the key word there. ... Peer—somebody that's related, somebody that's got some same issues, right? And so if you're my peer, can you understand, can you help me. You can feel what I'm feeling. ... The key there is to recognize the peer counselor is a relational thing. And you keep focused on that ... the relation ... because people can get counseling. Somebody's got a Ph.D. and they're going to tell them something, but where's the relation?

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Once counselors gained entry to others' lives, the relationship could become more of a two-way, mutual experience, where HIV+ women "sit down and we can study together, and we can learn together, and we can grow together." When counselors felt they were successful in their work, it was usually because they had made a real connection with the peer client and had been able to develop a relationship based on mutual understanding and shared experiences:

> There [was] one that I really didn't think that I got to her. . . . She wasn't really concerned about improving herself. . . . She was just basically concerned about the money, . . . but there's a couple of them, they were very much trying to do better with their life.

In a few instances, peer counselors admitted their relationships occasionally extended beyond the prescribed limits of the peer counseling intervention:

> If my clients need a ride and need to go [somewhere] to pick up some money or pick up some food, if they call me, I'll go get them and take 'em. I'll take 'em. But they say I'm not supposed to do that. But I'm going to do it.

Work and Life Intertwined: Drawing on Personal Experience

Personal life experiences were an essential resource for HIV/AIDS peer counseling work. Peer counselors brought to their work their personal knowledge and experiences of being HIV+, taking care of themselves, seeking and receiving medical care, and navigating the health care and social systems as a client or employee. Putting this knowledge to good use by helping others was one of the primary motivations peer counselors identified:

> There's not too many things I haven't been through with the disease, so you know. . . . Gosh, why not try to help somebody else?

First-hand experiences of having been the recipient of assistance from others, whether a friend or a support group, reinforced the value of a supportive relationship in time of need:

> 'Cause there was a couple of people that kind of took over for me when I finally went through the PCP [pneumocystis carinii pneumonia] and had to deal with the AIDS . . . and I had a really good friend of mine that just kind of jumped in there and took over, and her name is Sarah. . . . She is still a good friend, and I tell people all the time, "I do this because not everybody has a Sarah."

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Participants recognized loneliness as a characteristic of rural women's HIV disease experience; being present was one way peer counselors helped fill the emotional voids in other women's lives: "You can also sit and cry with them, if you have to. . . . A lot of these women have nobody."

Peer counselors embodied messages of hope, resilience, and the desire to help others. "Because we have this disease don't mean we got to lay down and die." "I love people. I'm HIV+ and I try to help others that's HIV+. Give them a positive outlook." Having a positive message was an integral part of their own being and their work as peer counselors: "So I just wanted them to know that you're still a viable human being and this is what you have to know about yourself."

There was also a sense of mission and a desire to share personal successes with peer clients:

> I tell them about the school I go to and I don't pay. They gave me a 4-year grant just to go to school. And I tell them, "Just go to job service and sign up for this school called WIA and they'll send you to school for your diploma. If you got your diploma, they send you further."

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Prior personal experiences of not having had sufficient information, resources, and support also motivated peer counselors to help others. At the same time, they were quick to acknowledge the inherent limitations of each individual's experiences: "If I have experienced it, then I let them know. But if I don't have experience, I can't let them know."

Resources the counselors brought to their work included personal knowledge of health and self-care practices and experiences of participating in HIV support groups. They drew on both their positive and negative experiences. A common motivation was the desire to assist others in ways that they had been—or would liked to have been—helped. By looking back and reflecting on their own struggles, counselors identified ways to help others avoid problems and prevent possible mistakes. This counselor drew on her personal experience of having tried to navigate the health care system without information or support:

> Because I didn't know where to go or who to talk to and I was afraid that . . . if I went to my doctor and it was on my insurance that my job was going to find out, and it was just easier to ignore . . . and had I had the resources, maybe I would have handled things a bit different.

Being able to put things in perspective and use humor was another strategy that peer counselors used in their own lives and their counseling work. They drew on their own struggles and successes. This story illustrated how one counselor gauged a client's progress by the woman's ability to acknowledge her HIV status and interject a bit of humor into her personal

coping repertoire. At the same time, the peer counselor reflected on her own personal strategies for keeping a balanced perspective on her health status:

> Like, there was time when I'd go over and they would not really just want to focus on the HIV thing. . . . There was one that would not joke about it because everything was so serious about AIDS. A couple of times I popped a joke about it and she just looked at me strange. Then when the sessions were about halfway through, I called her and I said, "How are you doing today?" And she said, "Like I have AIDS today; I feel like crap." This is something that she would never have said; she would have said something like, "I just don't feel too good today." She would never joke it off like, "Oh, it's an AIDS day." I mean small steps in some ways, but a big step in others. Because she would say, "I don't feel too good today. I don't know why. I slept good last night. I'm just so tired." And I'm thinking to myself, "Okay, you've got 40 T cells. That's why you don't feel too good today." I tell people, "You know, sometimes everything that goes wrong healthwise, I blame it on HIV. But I have to also realize that I'm 43 now."

The Personal Work of Facing Fear and Stigma

A significant component of peer counseling work focused on issues of fear and stigma of HIV at the personal, family, and societal levels. One counselor approached fear and stigma as public relations work:

> I talk to people about that all the time. That there isn't a sign across our heads. . . . It used to be people would say, "Ooh, he looks like he's got AIDS." Now I look at people and say, "What do they look like?" You know, I mean I have people talking to me and say, "Well, I really don't know anybody that has AIDS." And I'm thinking to myself, "Well, you *do*."

Another counselor described the process of helping other HIV+ women overcome internal and external barriers created by fear and stigma as a process of "opening doors." This was not merely a metaphor—it was a description of a creative, but very real, way of demonstrating to another woman how the stigma she felt was invisible to others:

> Because she wouldn't go to any of the meetings or anything like that . . . because she felt—heck, she felt like [if] she walked out to her mailbox—she would not even walk out to her mailbox. She would go grocery shopping in the middle of the night, when the store was empty. . . . She felt like she had this sign across her forehead. . . . The way that I got her to go is one day I went over and picked her up for one of our sessions and we actually went out to eat lunch. And I told her, I said, "Look, nobody here even knows that we're HIV+. The waitress is

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> waiting on us just like she's waiting on everybody else. The hostess sat us just like she sat everybody else." And that was like opening the door for her.

Recognizing Diversity of Experiences: Tailoring Peer Counseling

Peer counseling is complex work, and the women clearly recognized that they could not apply a "one size fits all" approach to their work. Although they relied extensively on their personal experiences as a resource, they also acknowledged that personal perspectives and approaches to managing HIV disease would not always work for others. As one woman noted, each individual has to be comfortable with her personal approach to the disease:

> She was like, "Well, I just really . . . think those medications are toxic." And I'm like, "Oh yeah, of course they are." I'm not going to sit there and tell you they're not. Sometimes the side effects are worse than the disease itself, but it's a proven fact that they're keeping people alive. . . . I said, "You know, I just don't' even find out the side effects from medication, because just as sure as I get them in my head, I'm going to think I've got them." So the people have to handle things the way they feel best for themselves.

Although they drew heavily from their own experiences, the peer counselors also recognized they could not use their own experience as a template to judge or approach others: "Don't go in being judge and jury, because you of all people should know that feeling." Just as they worked to help others overcome their fears of stigma, the peer counselors themselves recognized their own need to be open-minded about others:

> To be open-minded. Not everybody's situation is the same as yours. . . . Don't go in there and look down on the people because they were an IV drug user and that's why they got infected because that's not how you got infected.

The ability to develop a "successful" peer relationship could not be taken for granted. Peer counseling work presented these women with the ongoing challenges of maintaining honest, open, nonjudgmental relationships and a willingness to take risks to help others:

> [Peer counselors need to] be gentle, but to always be honest. . . . It's important that we be honest with others. We don't tell them lies just to make them feel better. . . . To encourage, to inspire. . . . Don't be demanding and make people feel like they failed because they didn't reach your goal. Just to be helpful.

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When the Peer Counseling Work is Done: Terminating Personal/Work Relationships

Because peer counseling was eminently personal relationship work, an inherent challenge and potential emotional cost to counselors was the termination of those relationships when the research was completed or a client died. The counselors disclosed ways in which they managed the termination, which in some cases meant having some form of continued contact:

> I knew that it was going to be over, that was the hard part. . . . What do they do when it's over? So what I tried to do . . . was to show them something in them to hold onto, after it [peer counseling] was gone. You know, I'm not going to be here always. But I tried to form relationships where we call each other, or we correspond by cards or stuff like that. You'll always be in my heart, but you're gonna have to know how to handle this thing after I'm gone. That's what I wanted them all to know. It would be ideal if we could, you know, get them and bring them to things because out there they have nothing, but that just hasn't been set up yet.

Counselors handled termination from different perspectives. Some agonized over how and when to terminate the relationships with a peer; others were more comfortable in either drawing the line or crossing it when the intervention was complete. It was clear, however, that while HIV/AIDS was the primary focus of peer counseling work, because of the nature of the close personal relationships that developed over the course of the intervention, some relationships continued after the research was completed:

> There's still a couple of them that'll call me or from time to time I'll call them and talk to them and just see how they're doing . . . because we didn't always spend just time over there and the whole conversations was about HIV and AIDS and all that stuff. Sometimes I'd go over there and they'd want to look through photo albums from their past. . . . I mean, sometimes they just needed the comfort of somebody just like them.

Terminating a personal relationship elicited conflicting feelings and responses among peer counselors. There were reports of difficulty in coming to terms with the end of the program on the part of both peer counselors and recipients of the intervention. For both parties, it could be difficult to draw a clear line distinguishing a peer counseling relationship from friendship:

> She felt like she had a friend. . . . I feel that I failed her because I haven't called her back. . . . I guess in a way it's . . . it may be about a job, maybe I don't want to continue because I feel like when I do talk to her, she's going to want me to meet her somewhere so we can talk. What she tells [the people at] the clinic is she just needs to talk to me. [She asks them,]

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> "Why did she quit coming to see me?" They try to explain, "Look, it was a study."

Counselors also expressed conflicts about the value of continuing contact with clients who had ongoing issues, particularly with drug abuse. This counselor recognized the limits of the peer intervention and realized that continuing the relationship was not necessarily the solution:

> Like that one lady I was talking about, she's begging for me to call her and I'm in a position [that] I don't know if I should or not, because I think I made such an impact on her, I think it would become a regular thing . . . and I don't mind, she could talk to me, but she's going to have to make the choice to quit [using drugs]. . . . I told her, "You can talk to somebody all day long, but until you decide to quit, I'm not going to be able to help you."

Not all peer counselors felt conflicted about continued contact. In some cases, ongoing relationships were not an option. Dealing with the loss of a counseling a client until death was part of the job:

> But I'm saying . . . there's pros and cons with it. . . . I think there's more pros than cons, because I met some really great, great people that I still do stay in touch with. Unfortunately, I did have a couple that passed away during the time that I was seeing them. . . . That's rough, getting close to people [who die].

Assessing Risks and Benefits of Peer Counseling Work

Embodying the HIV/AIDS experience and serving as an example and resource for other women with the same condition required personal scrutiny and an honest recognition of the limitations of this challenging, but often rewarding, work. Being a peer counselor entailed potential physical, emotional, and health risks, including facing the unknown, emotional stress, visiting homes in dangerous neighborhoods, being taken advantage of, and exposure to potential infectious agents. One peer counselor described how she navigated unknown territory with each new client in order to come to know and anticipate her own potential risk exposure:

> There's risk involved in it . . . especially with there being money involved. I ran into that at times . . . seeing some of the girls because they need that money . . . And even though they know I'm HIV+ too—as a matter of fact that I have AIDS—because they know my appointment is set up and I'm coming over and they need that little bit of money that's coming in, they don't tell me, "Well, by the way I've got a really bad cold." So maybe [you] go visit. . . . But really, until you talk with somebody a few

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> times, you really don't know about the person, ... but that person isn't going to say, "Yeah, I'm still using drugs, blah, blah, blah" They're going to say, "Well, no, I've been clean."

On occasion, counselors would refuse to take on a client or to make a visit, in order to protect her own physical and mental health:

> There was one [woman] that they wanted me to go see. ... They were saying, "You know, she's been pretty sick and her T cells are pretty low." I wouldn't go see her. I said, "No." I didn't feel like I was going to be of any help to her and it was probably going to pull me down, so I don't want to compromise my health or my well-being either, not as far as just picking up something from her, an illness or anything like that. Mentally, at that time, I just didn't feel like it was the right thing for me, because there was one that I went to see. ... She was pretty much so sick already. ... She wasn't taking any medications and I knew even if she started taking medications it was too late, because her viral load was 700 and something thousand and she had like three T cells. I was like, "No, I'm not putting myself in that kind of situation."

Another identified risk was that the counselor–client relationship would "*go too far*" and the counselor would feel that a client was using or taking advantage or her:

> You've got to remember to tell them the resources. There are some resources out there for them; that's what I ended up doing. I did get some old clothes, stuff like that for some. But you can go too far and if they see that you're going to help, they will try. ... Some women will use you ... for a pack of cigarettes, that kind of stuff.

HIV/AIDS peer counseling work entailed potential exposure to physical and emotional risks or exploitation. There was, however, a clear consensus that the benefits far outweighed the risks. Each of these HIV+ peer counselors continued to face challenges in their own lives. Having their own lives and experiences recognized and acknowledged as a valuable resource for others was in and of itself meaningful. Being identified as someone who could relate to others with HIV validated these women's life and work:

> I had been going to support groups and stuff like that here in Brown County and every now and then a couple of people that were involved in the support group would get a phone call and say [to me], "I think she could probably relate to you and your story, so why don't you give her a call or [invite her] to the support group meeting this week." So the fact [was] that that was the only experience that I really had. ... It's just life.

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It often took considerable time and effort before the benefits of peer counseling became manifest. The following story illustrated the comprehensive nature of a peer counselor's commitment to helping another HIV+ woman with complex and challenging issues. The results of her persistence and dedication became evident over time, as the counselor witnessed the woman taking concrete action and visibly improving her health in the process:

> There was a girl that I was going to see that had two kids. All she was talking about was, "I just want to make sure that I live until these kids are 18 years old." One was just a few months old. And she wasn't seeing a doctor or taking any meds. She was real slow, she just wasn't real intelligent at all and I had to kind of steer her in the right direction. Now she's going to the doctor and she takes her medication every day. She's had her tubes tied since then. She's back on her medications. She takes walks every day for exercise. She tries to eat right. She's doing everything she can. She's actually taking action.

Helping others overcome personal and societal fears and stigma and taking action to improve their own health and well-being were challenging but very rewarding aspects of peer counseling work.

DISCUSSION AND IMPLICATIONS

Based on these insiders' descriptions and perspectives on the work of HIV/AIDS peer counseling in the context of a rural community-based program in the southeastern United States, we can contribute to the extant literature on peer interventions, and, more specifically, the theoretical and practical understanding of the experiences of women engaged in the work of HIV+ peer counseling. The RWHP peer counseling intervention was designed to address the stigma, fear, social isolation, and multiple barriers to information, resources, support, and health care that are common among women living with HIV/AIDS in rural U.S. communities. Across the globe, HIV+ women face similar issues. Practitioners and researchers in diverse settings may apply these research findings in their efforts to more clearly define the HIV/AIDS peer counselor role, recognize its limitations and challenges, and support more effective and appropriate implementation of peer interventions designed to reach geographically isolated women. The findings of this study may also provide guidance in the development, implementation, and assessment of peer training and support programs in the context of HIV/AIDS and in other women's health programs. Peer health advocates, practitioners, and program administrators, however, must assess the applicability of the findings of this study to the social, economic, and cultural

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contexts and settings of other HIV/AIDS peer intervention programs (Campbell & Mzaidume, 2001).

Participants in this study identified personal benefits of assuming the peer counselor role as well as problems, challenges, and difficulties in carrying out their work. Their experiences and perceptions confirmed, but also challenged, some of the assumptions regarding peer interventions. Their similar HIV status and experiences did enable them to access, connect with, develop relationships and trust, and provide support to other HIV+ women. These peer counselors clearly recognized, however, the limits of their personal experiences and the diversity and differences among HIV+ women. In order to be effective in their peer counseling work, these women had to take these differences, and their own personal health, safety, and resources, into account.

Central to the peer counselors' experiences were their desire to help others and the therapeutic use of self. The desire to help others is a key theme among women with HIV disease, particularly as they succeed in learning about and managing their disease and the illness experience (Moneyham et al., 1997). The desire to help others may be a part of the process of finding meaning in their illness, a process that has been noted in theories and research of adaptation to chronic illness (Morse & Johnson, 1991). The ability and willingness to share one's own personal experiences with others was viewed as key to helping others. Other recent community-based research has shown resilience and a positive outlook among HIV/AIDS peer counselors (Harris, 2006).

These peer counselors recognized the intrinsic value of *being themselves* and communicating their experiences, knowledge, challenges, and successes to others. They also were quite clear on the need to be able to share relevant experiences with other HIV+ women. They were able to review and select personal experiences that they thought fit the context of their clients' experiences. In this way, they attempted to individualize the counseling in order be meaningful to other women's experiences. Their embodied work involved serving as role models, developing relationships, and inspiring hope in other HIV+ women. These findings support the cultural and contextual relevance of the peer counseling approach in supporting rural and disenfranchised women as they learn to cope with HIV disease (Jimenez, Algeria, Pena, & Vera, 1997; Levine, 1983; U.S. Department of Health and Human Services, 2004) and are also applicable to HIV+ women in urban settings.

Participants understood that in addition to personal, one-on-one support, their job was to connect HIV+ women with existing resources. Personal experience was a source of knowledge and information regarding existing resources. In any context, prior personal experience among peer outreach workers will vary, and therefore ongoing peer counselor training and capacity building must include updates on the availability, eligibility, and access to local health, social, and economic resources. Peer counselors also need

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training and support to develop an appropriate repertoire of behavioral responses for use with different clients. In particular, peer counselors need to develop a critical awareness of personal responses to client behaviors that potentially could foster dependency (e.g., doing things for the woman that she can do for herself). Peer counselors may need guidance in developing strategies that provide support while empowering others to act on their own behalf. The need for realistic expectations for outcomes of peer interventions was emphasized by the RWHP peer counselors who measured the success of their work by the *"small steps"* they saw their clients take.

Participants in this research clearly identified personal risks and challenges in their peer counseling work. These findings echo the feelings of discomfort or apprehension working in unfamiliar or unsafe locations reported from an assessment of another peer-led HIV prevention program among minority and female drug users (Dickson-Gomez et al., 2006). Awareness and prevention of potential risks, including environmental exposure (e.g., to disease, violence, drugs) and personal relationship abuse (e.g., coercion, exploitation, being "used"), must be addressed in the design and oversight of peer counseling programs, regardless of the context. The success or failure of peer-based interventions depends not only on the mobilization, training, and support of local individuals, but also on the ways in which structural conditions of poverty, gender inequality, and health inequities permeate the fabric of local communities. As Campbell and Mzaidume (2001) aptly noted in their examination of the processes of grassroots participation, peer education, and HIV prevention by female sex workers in South Africa, "It is simplistic to assume that the mobilization of local community networks and resources . . . will automatically yield positive benefits" (p. 1984).

Peer interventions are based on social and interpersonal relationships and commonly occur in community settings rather than in clinical settings. Characteristics of the formal health care system include professional distance, a high level of technical knowledge, a detailed division of labor, and short-term commitment (Messeri, Silverstein, & Litwak, 1993). In contrast to professionals who provide services within the formal health care system, the RWHP counselors conducted their work primarily within the homes of their HIV+ clients. As they provided personalized counseling and support, the confluence of several factors (e.g., common HIV+ status, informal setting) provided fertile ground for the blurring of boundary roles (Allen & Ciambrone, 2003). As a result, some peer counselors found the work of terminating personal relationships that had become an integral part of their work and personal lives to be very challenging. There is a need for further examination of how the particular personal, cultural, social, and economic dimensions of peer interventions may contribute to the formation of peer relationship identities and how policies designed to limit or terminate interactions impact peer participants on both sides of the relationship. When HIV/AIDS peer counseling interventions are time-limited, it is important to

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connect participants with other supportive networks prior to termination. Expansion of HIV+ women's social networks can also mitigate undue dependency on an individual peer counselor.

Our findings corroborate other research on the mutual benefits of providing peer support to HIV+ women (Arnstein et al., 2002; Brunier et al., 2002; Campbell & Mzaidume, 2001; Raine, 2003). These peer counselors identified ways in which they had been transformed by the experience of helping others. Similar findings were reported in a study of volunteer community work among women living in economic poverty (Messias, DeJong, & McLoughlin, 2005a). Volunteer work in the community was a means through which economically poor women became involved and made connections with others, gained knowledge and skills, increased their self-esteem and confidence, empowered themselves and others in the process, and built community. The authors noted that for women who "are likely to experience material deprivation, social marginalization, alienation, insecurity, fear, and frustration ... volunteer community involvement provided an alternative context—that of being active contributors to the community rather than marginalized recipients" (p. 83).

The RWHP peer counselors clearly valued their own work and recognized its impact on others and on themselves. In a variety of ways they made visible what is often invisible—the stigma and fear that HIV+ women experience as well as the transformative change that can result from individual and collective empowerment. Internationally, there is the need to develop interventions for communities marginalized because of economic, social, immigration, sexuality, or health status. We also suggest that practitioners, researchers, and policymakers need to reexamine the way they conceptualize and operationalize women's work in the context of marginalization (Messias, DeJong, & McLoughlin, 2005b). Because the work carried out by peer counselors often occurs naturally among members of a community, like the value of women's work, the value of peer counseling may not be readily recognized. For peer counseling interventions to reach their full potential and impact, the work must be fully acknowledged not only by those on the inside, but also those in health and social service sectors working within these communities.

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